Families affected by HIV/AIDS in Kyasands Informal settlement

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ABSTRACT

The statistics on HIV/Aids in this study overwhelm the imagination. It has great social and economical consequences for individuals, families and communities. The generation of between 15-24 years are vulnerable to infection especially women. From the population of about 46 million in South Africa, 5.7 million were HIV positive by the end of 2007 with about 1000 deaths every day. Sub-Saharan Africa appeared to be the most hit by this tragedy as indicated by statistics in this study. When parents die of Aids, the burden of orphaned children is left with relatives and extended families to look after those children. The number of orphans is escalating due to increasing death rate of parents. A detailed discussion on the extended families which includes their origin, roles they play as well as challenges they face in caring for orphaned children is included as well. Challenges include having to deal with grief and changing behaviour of the orphaned children.

The goal of this study was to conduct an analysis of extended families affected by HIV/Aids taking care of orphans, living in the Kyasands informal settlement in order to improve service delivery. The main objectives of the study included exploring the needs of these extended families caring for orphaned children in terms of social, emotional and material aspects as well as challenges they face and how they manage to survive. A qualitative method was used in conducting this study with the use of semi-structured interviews to collect information. The main central question asked was, *how do you manage to live with an additional member within your family.*

The main findings in this study were reported which included the strength and composition of assets and the extended families' resources to make a living and adjust to shocks of life. Family was seen as the most trusted asset in this study by the respondents. Just to mention a few, most of the families owned shacks, battery operated radios and televisions since they live in formal settlement without any permanent infrastructures.

Caring for orphans means having an extra family member to care for who comes with his or her needs and brings along own needs and brings along challenges in families; including brought about by loosing family member due to HIV/Aids. To mention just a few findings, grief influences behaviour especially that of children who might develop anti social behaviours that their caregivers must understand. Grief is no respecter of persons both orphaned children and their care givers suffer emotional disruption which affected and changed their behaviours.

On the other hand, stability within families was affected. When children are moved from their family homes to stay with extended families or siblings separated to different families. The family structures were affected as well; due to additional family members with additional expenses, which included inability to afford basic needs like food and clothing. In addressing the issue of expenses, the government assisted in the form of social grants to augment care-givers part time salaries. The Non-governmental organizations (NGO), Faith based organinizations (FBO) and Community based organizations (CBO) provide material assistance to these extended families. FBO's also provide spiritual upliftment.

It was concluded that extended families need support due to the circumstances they face in their lives. Government is playing a vital role within these families as most of them depend on the social grants for survival. Recommendations were made towards all service providers rendering service benefiting extended families caring for Aids orphans in order to contribute to their sustainability and quality of life. Issues regarding destigmatization are to be addressed by service providers in addition to the campaigns they have regarding HIV education. Families affected by HIV/Aids need psychosocial support from social workers, psychologists and all other professionals rendering service to families caring for Aids orphans as some are ostracized and stigmatized by communities since they care for Aids orphans.

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CHAPTER 1

GENERAL ORIENTATION TO THE STUDY

1.1. INTRODUCTION

According to UNAIDS reports (2006), nearly two-thirds of all people living with HIV are found in Sub-Saharan Africa, although this region contains little more than 10% of the world's population. The effects of this problem have been mostly seen in illness and death. The impact of the epidemic has certainly not been confined to the health sector only; households, schools, workplaces and economies have also been affected. During 2006 alone, an estimated 2.1 million adults and children died as a result of Aids in Sub-Saharan Africa (UNAIDS, 2006). UNAIDS estimates that there were 1 200 000 orphans due to Aids, living in South Africa at the end of 2005.

Considering the above statistics on HIV and Aids, it shows that the toll on households and families can be severe. Families who are affected by HIV/Aids in all likelihood have unique problems and needs. In many cases, the presence of Aids causes the households to dissolve, as parents die and children are sent to relatives for care and upbringing (Jackson, 2002). This study will focus on the coping mechanisms and strategies of extended families taking care of the orphaned children. The researcher's intention is to explore the challenges facing extended families affected by HIV and Aids, and how they manage to survive.

1.2. MOTIVATION FOR STUDY

According to Jackson (2002), a family is an institution where its members feel a sense of belonging. If HIV infects one family member, the remaining family is automatically affected one way or the other. The problem starts when parents die and leave children with the extended family, either grandparents or uncles and aunts. Orphans left with extended families are regarded by the Child Care Act 74 of 1983 as children in need of care. The Social workers' interventions in this

matter are statutory work placing children in foster care placements and institutions.

According to Niehof (2003), the HIV/Aids pandemic represents a great threat to rural communities particularly in Sub-Saharan Africa. He further indicated that morbidity and mortality due to HIV/Aids affects families, resulting in a reduction of their ability to generate livelihood and adjust to the future shocks. How extended families manage to survive under conditions caused by HIV/Aids is unclear, hence it is imperative to understand and explore their coping mechanisms.

1.3. RESEARCH PROBLEM

The extended family members who are left behind with the children after their parents die of HIV/Aids related sicknesses face challenges bringing them up. USAID (2004) reports indicated that orphans adjust easily if they remain in familiar surroundings, in family units they know. According to Steinberg (2002), the challenges faced by extended families who take in an orphaned child include dealing with increased household expenses as well as changes in family structure. This means they have to deal with an extra family member with extra expense. The orphan also has to deal with the emotional trauma of losing parents and adjust to a new lifestyle with the extended family.

The researcher was employed as a social worker at Witkoppen Clinic in Fourways and it was identified through work experience that the number of foster care applications has increased due to the increasing number of HIV/Aids orphans. An analysis of these extended families affected by HIV/Aids was necessary, especially those staying with children who lost their parents due to HIV and Aids. Data collected will assist in terms of understanding their position so as to be able to make recommendations towards improving quality of service they receive. This study hoped to explore problems and needs as well as coping mechanisms of extended families in Kyasands Informal Settlement, caring for Aids orphans.

1.4. THE RESEARCH QUESTION

The following question was formulated based on the above problem statement: What are the challenges faced by extended families caring for HIV/AIDS orphans?

1.5. GOAL OF THE STUDY

The goal of the study is to conduct an analysis of extended families affected by HIV/Aids taking care of orphans, living in the Kyasands informal settlement in order to improve service delivery.

1.6. OBJECTIVES OF THE STUDY

- To explore the problems and needs of extended families living with orphans, who lost their parents through HIV/AIDS in Kyasands informal settlement, in terms of social, emotional and material aspects.
- To conduct an analysis of the assets of extended families affected by HIV/Aids.
- Determine how households respond to the needs and challenges they face.

1.7. OVERVIEW OF RESEARCH METHODOLOGY

The extended families caring for orphaned children whose parents passed away due to HIV/Aids were analysed. Focus was mainly on the needs and challenges of these families, their assets, services available in their community and their coping mechanisms. The study focused on how people strategically use the resources available to them to address challenges they face.

The research design used in this study is classified by De Vos (2005) as exploratory, as it seeks to explore a particular phenomenon thoroughly, the purpose being to develop ideas and theoretical generalisations.

The population group for this study was extended families affected by HIV/Aids

who were staying with HIV/Aids orphans residing at Kyasands informal settlement (an extended family may include either grand parents or uncles and aunts).

A purposive sampling method was used to collect data (De Vos, 2005). This type of sampling method of research is based on the judgment of the researcher in choosing respondents (De Vos, 2005). The researcher interviewed only those extended families affected by HIV/AIDS, who visited the welfare office during the past one year, who have lost a member of the family due to HIV/Aids and who left behind children with them who need care. Grand parents, aunts and uncles from the African race were the ones interviewed because the community of Kyasands comprises mainly of the African race. All adults were interviewed both male and female as long as they are extended family caring for HIV/Aids orphans. This included 18 respondents.

A qualitative research study was conducted using qualitative interviews. Interviews were used due to the sensitivity of the subject. Data collection consisted of semi-structured interviews with open ended questions (De Vos, 2005).

Qualitative data analysis methods according to Creswell (1998, 2003) were used. Data was from semi-structured interviews (See semi-structured interview schedule in Appendix B) as well as field notes with consent granted by participants. A technique to confirm trustworthiness included member checking. This involved confirming the findings from all respondents after the research. It included finding out from the respondents whether the findings were a true reflection of what they told the researcher during the interview.

The tradition followed in this study was content analysis. The steps followed during data analysis included data coding, looking for patterns in data and generalisation from themes and interpretation. The raw data was coded using open coding. Data was sorted into categories, themes and ideas (Denzin & Lincoln, 2000). (See example of the analysis of raw data in Appendix E). More

detailed discussion on the research methodology was done in chapter 3.

1.8. ETHICAL CONSIDERATIONS

The researcher ensured that research participants were informed about the purpose and the content of the study. They were also informed about their rights to participate or not to participate in the study. Personal identities of respondents were treated confidentially and the information supplied was used for purposes of this research only and for no other reason (De Vos, 2005). Only assumed names were used in this study to protect respondents' anonymity.

No promises were made to participants since those who have problems might expect help from the researcher. The researcher used files from the social welfare department in Witkoppen Clinic. She (the researcher) requested permission from the management to screen the files and select the samples. Selected samples were contacted telephonically to let them know about the study. Respondents signed a consent agreement to be interviewed. The consent letter was read to those who did not know how to read or write and they gave verbal consent.

1.9. CONTENT OF CHAPTERS

This study will be divided into five main chapters as follows:

Chapter one provides a description of the general background to the study and includes aspects such as motivation for study, research problem as well as the research question.

Chapter two includes the literature review on HIV/Aids as well as a review on care giving, informal settlement and extended families.

Chapter three answers the question of how the study was conducted. The

research methodology and data collection methods are described in detail.

Chapter four includes the findings and the interpretation of the study.

Chapter five provides the conclusions and recommendations.

1.10 LIMITATIONS OF THE RESEARCH

It is difficult for many people to talk about their HIV status in fear of shame and stigmatisation and this was one of the main limitations to this study. The researcher is employed on full time basis and time was one of the limitations as well as transport expenses since she was using the qualitative method which takes a lot of time to collect data. Kyasands is an informal settlement without proper roads to drive on and this also contributed to the problems anticipated with this study. The researcher had to walk around the settlement to meet her respondents which was risky especially because she did not know anyone in the area.

1.11. DEFINITION OF CONCEPTS

AIDS refers to Acquired Immunodeficiency Syndrome. AIDS represents only the end stage of a continuous, progressive pathogenic process, beginning with primary infection with HIV, continuing with a chronic phase that is usually symptomatic, leading to progressively severe symptoms and ultimately, profound immunodeficiency and opportunistic infections (Fauci, 2000).

Extended family includes many families living under the same roof, depending on circumstances. In extended families, the network of relatives acts as a close-knit community. This can include (aside from parents and their children), cousins, aunts, uncles, foster children/ adopted children. In many cultures, such as in those of many of the Africans, extended families are the basic family unit (Kimani, 1998). Kimani further indicated that, in African culture, extended family members had certain functions to perform like taking care of orphaned children

and taking care of each other.

Family is a group of people who are closely related by birth, marriage, or adoption living together and functioning as a single household**,** usually consisting of parents and their children (Crowley, 1995).

HIV refers to Human Immunodeficiency Virus. The presence of HIV infection does not mean that a person has AIDS. This occurs when the infection has severely damaged the immune system, a process that may take years (Jackson, 2002).

1.12. CONCLUSION

In this chapter an attempt was made to explain the context of this study which is exploring the challenges faced by extended families caring for Aids orphans within the Kyasands informal settlement. An introduction was made as to why the study was conducted and a motivation for the study was given. The goal and objectives of the study were formulated as well as a discussion of the research methodology, and data collection. The result of this study will contribute to the kind of services rendered to these families by local service providers and social workers. Recommendations will be made to them in order to guide them in their intervention with these families. This will also contribute to the general improvement of services and also a clear understanding of these families' way of life and how they manage to live under those circumstances.

CHAPTER TWO

LITERATURE REVIEW

2.1. INTRODUCTION

This chapter will be divided into two sections namely an overview of HIV/Aids which includes the current situation of HIV/Aids in South Africa and its economic impacts as well as HIV/Aids and the orphaned children. Statistical estimations of HIV and Aids are also addressed in this chapter. The second section includes a discussion of extended families, their roles and the challenges they face in caring for Aids orphans.

2.2. HIV/AIDS – AN OVERVIEW

2.2.1 Introduction

HIV infection and Aids have emerged as the most challenging health matter of modern times. Although it is incurable at present, it is considered a manageable threatening disease (Jackson, 2002). Despite a growing awareness and concern worldwide, many people in South Africa still believe that HIV/Aids does not really exist or that it only affects certain groups of people, such as prostitutes and gays (Claxton & Harrison, 1991).

According to Patel (2005), HIV/Aids have reached pandemic proportions in Africa, and especially in Sub-Saharan Africa. Patel further explains that this has had great social and economic consequences for individuals, families and communities. In Sub-Saharan Africa, 20 million people are estimated to have HIV/Aids. Young people less than 25 years and women have the highest infection rates. Women between the ages of 15-24 years are more vulnerable to HIV infection than men (UNAIDS, 2004). The situation in South Africa is discussed in the following section.

2.2.2. HIV/Aids Current situation in South Africa

Southern Africa remains the region worst affected by the HIV/Aids epidemic. A combination of factors seems to be responsible for this including: poverty and social instability, high levels of sexually transmitted infections, the low status of women, sexual violence, high mobility (particularly migrant labor), and lack of good governance (UNAIDS, 2004). All these happen in a society where approximately 61% of South Africa's 18 million children live in Poverty and 7.9 Million people are unemployed (UNAIDS, 2004).

The HIV/Aids pandemic is placing pressure on systems of care and support, including health, family and community systems. Kwazulu-Natal, Mpumalanga and Gauteng provinces continue to show an increasing trend in HIV prevalence in South Africa (South African Epidemiological Fact Sheet 2002 in AIDS Review, 2003).

South Africa has the sixth highest prevalence of HIV in the world, with 18.8% of the population estimated to be infected. The UNAIDS 2006 Global Report, estimated that 320 000 people died of Aids related deaths in South Africa during 2005. According to the 2008 Global Aids Report, South Africa is currently experiencing one of the most severe AIDS epidemics in the world. At the end of 2007, there were approximately 5.7 million people living with HIV in South Africa, and almost 1,000 AIDS deaths occurring every day. New infections are still increasing with no signs of reaching a natural limit. The total number of South Africans living with the virus at the end of 2005, was estimated by UNAIDS (2006) to be in the region of 5.5 million. This annual survey uses a statistical model to estimate the prevalence of HIV in the population based on the prevalence among women tested at state antenatal clinics. The national average of HIV+ women attending antenatal clinics in 2005 was 30.2%. The province of Kwa- Zulu Natal continues to have the highest prevalence at 39.1% followed by Mpumalanga at 34.8% (UNDP, 2006).

Vulnerability to, and the impact, of the HIV/Aids epidemic is proving to be most catastrophic at community and household level. Hundreds of people of all ages

die in South Africa every day of AIDS related diseases.

The hardship for those infected and their families begin long before they die, with the stigma related to suspected infections. The fear and despair that often follows diagnosis; the loss of income and support when a breadwinner or caregiver becomes ill; the diversion of household resources to provide care; the terrible burden upon family members, particularly children caring for terminally ill parents, and the trauma of bereavement and orphan-hood also contribute to the hardship (Desmond & Gow, 2001).

For many years, the burden of care and support has fallen heavily on the shoulders of impoverished rural communities where sick family members return when they can no longer work or care for themselves (Jackson, 2002). However, it is dangerous to assume that communities have limitless resilience and capacity to care for dying people and provide for those they leave behind. There is an acute need for social protection and interventions to support the most vulnerable communities and households affected by this epidemic. This has to a large extent affected the social economic status of families when they lose breadwinners and have to adjust to new ways of living (Jackson, 2002). They have to look after orphans who bring along extra expenses in the extended households.

On average in South Africa there are three women infected with HIV for every two men who are infected. The difference is greatest in the 15-24 year age group, where three young women for every one young man are infected (UNAIDS, 2006). The South African Government's response to the epidemic is grounded in the HIV/AIDS and STD strategic plan for the period 2007-2011. The purpose of the plan is to provide a broad national framework around four priority areas: Prevention, Treatment, Care and Support; research, monitoring and evaluation; human and legal rights (Department of Health, 2005).

2.2.3. Economic Impact

No sector of the population is unaffected by the HIV pandemic. The poorest South Africans are most vulnerable to this epidemic and for whom inevitably the consequences are most severe. The impoverishing impact of HIV/Aids is so acute because it affects the economically active sector of the population and it is the breadwinners that are mostly sick and dying (Jackson, 2002). The impact of the HIV/AIDS epidemic is proving to be most catastrophic at family level. Increasing levels of HIV/Aids pose a serious threat to food security and nutrition in households. Families lose income earners, household expenditure is redirected to cover non- food items such as medical costs and funerals, children are taken out of school for lack of fees or to care for sick relatives, workers have to take time off to provide terminal care, resources may have to be shared with more dependents, and productive assets are sold off. Invariably the burden of coping falls on women, particularly girls and grandmothers (Jackson, 2002). Local organisations find themselves overwhelming with requests for support at the same time as they lose staff and volunteers to the epidemic.

2.2.4. HIV/Aids and Orphaned Children

HIV/Aids is the main contributing factor to the escalating number of orphans in the country of South Africa, which presently constitutes approximately 13% of the population (UNAIDS; UNICEF; USAID, 2004). As the HIV/Aids epidemic increases, so do the number of orphans and vulnerable children (OVC). Steinberg (2002) explains that, due to the average 10-year period between infection and death, even if HIV prevalence declined rapidly, South Africa would still experience an increasing orphan burden for many years to come. Children remain highly vulnerable to Aids (UNAIDS and WHO, 2001).

In Sub-Saharan Africa millions of children have already been orphaned and the numbers increase daily. They are at risk long before their parents die, not only through increased distress and poverty in the family as the breadwinners die, but also because of withdrawals from school and loss of opportunities for economic

advancement in the future. Their basic human rights are severely threatened. Young boys and girls grow up with little sense of security and hope for the future (Foster, 2000).

Obtaining accurate statistics on the number of children orphaned as a result of AIDS is problematic. Statistical reports on orphan hood are summarized as follows: If orphans are defined as children under the age of 17 whose mothers have died, UNAIDS (2006) estimated that there were 1 200 000 orphans due to AIDS living in South Africa at the end of 2005. UNAIDS estimated that there were 1.4 million South African children orphaned by AIDS in 2007, compared to 780,000 in 2003 (Global Aids Report, 2008). Once orphaned, these children are more likely to face poverty, poor health and a lack of access to education. According to UNAIDS (2008), there were around 280,000 children aged below 15 living with HIV in South Africa in 2007. Projections show that by 2010, 16 percent of all children in South Africa will be orphans and more than 70 percent of this will be due to AIDS (Dennis, Ross & Smith 2002).

UNAIDS (2000) estimated that by the end of 2000 about 13 million children in sub – Sahara Africa under age fifteen would have lost their mother or both parents to AIDS. By 2010 the number of orphans is projected to increase to 35 million (UNAIDS, 2000). In 2004, it was estimated that there are 2.2 million orphaned children in the country (Meaning 13 % of all children have lost either a mother or father) and nearly half of all orphans were estimated to have lost parents to Aids- related illnesses (UNAIDS, 2004).

Long before the emergence of the HIV/AIDS epidemic, the extended family in Africa has been taking care of vulnerable children and orphans. Today, development agencies are increasingly recognising the need to assist children affected by Aids (Foster, 2000). Support efforts to families are primarily community driven and owned, or at least be community supported with external assistance.

The worst affected children are those in deeply impoverished households who are losing their health (through infection, inadequate nutrition, and poor health care), their livelihood (through the illness and death of breadwinners and working adults), their parents (to illness and death), their families (as they are separated from care givers and siblings and sent with other relatives) and their social networks (Desmond & Gow, 2001).

The long-term legacy of HIV/Aids is the growth in the number of orphans who lose one or both parents, or caregivers. The impact of the HIV/Aids epidemic on orphans depends on a number of factors including the socio- economic status of their families, the size of the family and their age. Losing parents to Aids means that children have to assume new roles and new responsibilities within the nuclear as well as the extended family. Traditional roles, duties and responsibilities of family members become blurred, as AIDS places additional demands and pressure on orphans, particularly economic uncertainty, stigmatisation and emotional insecurity (Jackson, 2002).

2.3. EXTENDED FAMILY

This section includes a detailed discussion on the extended family which includes their origin, roles they play as well as challenges they face in caring for orphaned children.

2.3.1 The role of extended families

Study of the extended family has been integrated into multiple disciplines; chief among them are anthropology, sociology, and social work. From an historical perspective, extended family households have been studied extensively for their role in shaping the direction of social, economic, and demographic change (Hunter, 2000). From a sociological/anthropological orientation, extended family ties form much of the basis for understanding social networks in both traditional and contemporary societies (Nzimande, 1996).

Nzimande further indicated that the family is a social institution that binds two or more individuals into a primary group to the extent that the members of the group are related to one another on the basis of blood relationships, affinity or some other symbolic network of association. It is an essential pillar upon which all societies are built and with such a character, has transcended time and space. Often times, it has been mooted that the most constant thing in life is change, a phenomenon that is characteristic of the family irrespective of space and time. The dynamic character of family structures - including member's status, their associated roles, functions and interpersonal relationships - has an important impact on a host of other social institutional spheres, prospective economic fortunes, political decision - making and sustainable futures.

Assuming that the ultimate goal of all societies is to enhance quality of life, the family constitutes a worthy unit of inquiry. Whether from a social or economic standpoint, the family is critical in stimulating the well being of people (Nzimande, 1996). The family has been and will continue to be subjected to myriad social, economic, cultural, political and environmental forces that shape it. On the other-hand, as the subject of this study, an extended family is two or more adults from different generations of a family, who share a household. It consists of more than parents and children; it is the network of relatives that acts as a close-knit community. It may be a family that includes parents, children and spouses of children, cousins, aunts, uncles, grandparents and foster children.

The extended family may live together for many reasons, help raise children, support an ill relative, or help with financial problems. According to Modo (2001) sometimes children are raised by their grandparents when their biological parents have died or no longer can take care of them. Many grandparents take some primary responsibility for child care, particularly when both parents work. Extended families can be found all over the world in different communities and countries (Modo, 2001).

Extended family (or joint family) is a term with distinct meanings. It is used to refer to “kindred” who do not belong to the conjugal family. Often there could be many generations living under the same roof, depending on the circumstances (Modo, 2001). According to Modo, the influence of extended family members shows that although parents are the most important adults in the lives of children, non-parental adults may play important roles in the healthy development of young people. Extended family members may be the most important non-parent adults for young children, especially low-income families (Scales & Gibbons, 1996).

Extended family members are the most common non-parent source of adult support for children and adolescents; strong relationships with non-family members may be correlates with strong relationships with parents (Scales & Gibbons, 1996). Family members encourage youth to have supportive relationships with caring adults beyond the immediate family, such as a teacher, scout leader, or mentor (Benson, 1993).

All societies have a concept of extended family. Its relative importance, structure, and functions, however, vary according to the particular culture. Traditionally, the term extended family has been applied to the kinship network of social and economic ties composed of the nuclear family (parents and children) plus other, less immediate relatives. Study of the extended family unites two independent concepts: the household and kinship ties. The former refers to co-residence, whereas the latter implies relationship. When extended families share a common household, those most likely to be residents are the household heads' brothers and sisters, grandparents and grandchildren, and depending on the society, aunts and uncles (Scales & Gibbons, 1996).

The social and economic importance of extended family can most readily be seen when family members are living together; however, this does not discount the importance of kinship ties. Even in societies where extended families do not reside together and nuclear family households predominate, the nuclear family

may rely on extended kin to assist with basic day-to-day activities such as child or elder care and may be emotionally and economically codependent on family members outside the household (Scales & Gibbons, 1996).

Historical study is almost exclusively limited to examining the form and function of extended family households whose structures can be determined from census records, tax lists, and other widely available written sources. Researching extended families from a social perspective is more difficult because scholars must obtain possession of any surviving family diaries, journals, and letters in attempting to understand how extended family networks function across households. Interest in the history of the extended family households was kindled in the 1940s and 1950s as an aspect of population and development studies. At that time it was believed that the extended family household, prominent in many non-Western societies, stood as a barrier to economic modernisation. One popular position suggested that women living in extended families were likely to marry earlier and have more children, the resultant large families being defined as an obstacle to economic and social development (Castillo, Wiesblat &Villeral, 1998).

Contemporary perspective indicates that extended family ties and households have often proved remarkably adaptable to changing social conditions. It has been observed that the extended family is most likely to emerge in contemporary society when young adults face unemployment or divorce or when older adults become widowed and/or their health declines (Lee, 1999). The importance of extended family households and networks has also been shown among low-income urban African Americans; considerable research points to the benefits of grandmothers in single-parent households and extra-household extended family networks as important mechanisms for coping with inadequate financial resources (Pearson, 1999).

Goldstein and Warren (2000) indicate that the frequency of extended family

households has begun to decline in some Asian societies. The outlook for the extended family is unclear. At the same time, it is certain that as socioeconomic conditions, technology, and cultural values continue to change, so will the face of the extended family. New constructions of the extended family are inevitable in contemporary society. Recent family forms that pose a challenge as to who will be considered part of the extended family and the nature of these relationships include: same-sex couples with children living in extended family arrangements, children of open adoption who remain in contact with their biological parent(s), children conceived with reproductive technologies (e.g., surrogate motherhood) (Stone, 2001), and the relationships between stepchildren and their extended stepfamily.

Traditionally, in African culture the family unit is viewed as consisting of the husband, wife, and unmarried children, who form part of a larger family structure, the extended family. This is the ideal structure, and when a married son leaves the extended family to begin his own household, the process is known as fission. Viewed over time, black family life can be seen as moving from the extended to the nuclear type. However, the one has not replaced the other (Nzimande, 1996).

According to Ndzimande (1996), generally, in extended families, there is a wider group of people who are related by blood or marriage and who identify with and care for one another. The extended family is usually more stable than a nuclear family and extends over longer periods. The development and shrinkage of the extended family is affected by fertility, marriages, divorces, and deaths. In many communities it serves as a social service system that cares for and provides support to various categories of dependents. Notwithstanding the longer lifetime of the extended family, its existence is influenced especially by the greater economic independence of individual members, who tend to move out in order to live more independently in their own nuclear family.

Although the nuclear family functions more independently, its members usually

do not totally break ties with the family of origin or other important family members. During problems and in times of crises, members of the extended family are still expected to help and support one another. In many nuclear families a niece, nephew, aunt, or uncle is also present because he or she needs support.

2.3. 2 Challenges faced by extended families caring for orphans

Millions of children who have been orphaned by HIV/AIDS are cared for by extended family members but there is little information about whether adults can meet orphans' essential care-giving needs while working to economically survive. Due to care-giving responsibilities, family members are less able to supplement their income to accommodate orphans. At the same time care-giving responsibilities meant orphan caregivers spent fewer hours caring for their own children and other family members. Furthermore, orphan caregivers have difficulties meeting their children's needs focusing more on orphans (Chege, Mavimbela & Vermaak, 2002).

According to previous studies, after loss of parents, life changes for all affected family members and they are now forced to adjust to new ways of living and the challenges thereof (Steinberg, 2002). Some extended families staying with HIV/AIDS orphans are stigmatised and ostracised. This usually results in loss of respect within the community (UNAIDS, 2004). Unlike other chronic / terminal illnesses, HIV/Aids infection is further complicated by the stigma related to the transmission.

Due to disclosure fears and stigma associated with this pandemic, many families isolated themselves and their children from maltreatment (UNAIDS, 2004). Thus, they are cut off from valuable support. In conjunction with coping with the psychological and emotional ramifications of being affected by HIV/Aids, these individuals are forced to deal with a multitude of stressors with little support. These factors place these individuals and their family members at risk for mental

health disorders (e.g., depression, post traumatic stress disorder, and anxiety), developmental deficits, and behavioral problems (e.g., drug or alcohol use, school failure, inability to maintain a job, and criminal behavior).

Extended families have unique problems and needs. According to Modo (2001), HIV/AIDS changes family structure and function. Changing family structure includes changes in household size. Increase in numbers affects household spending due to additional members in the family (UNDP, 2000). Extended families are also faced with increased expenses which lead to deterioration of quality of households' diet and reduction in the number of meals (Chege, Vermaak & Mavimbela, 2004).

The socioeconomic status of households is low (Michael, 2000). For some extended families, apart from old age pensioners, their access to other grants is low due to lack of knowledge (Chege et al., 2004). These financial difficulties are the main reasons which lead to poverty. There are limited resources to meet children's basic needs especially those caring for HIV positive orphans. Resources include medical care and inability to afford good diet for them due to poverty. Some orphans run away from home due to poverty (Kayombo, 2002).

Most of the families are reluctant to take in Aids orphans due to the means test for accessing grants which discriminates against larger households. The income of the primary caregiver has to be below a certain amount, regardless of how many children are dependent on that caregiver. (The annual income of the caregiver especially foster care must not exceed twice the annual foster care grant). Furthermore, it is only payable in respect of a maximum of six children per household (Department of Social development, 2002). The grant therefore does not offer much assistance to families or grandparents caring for large numbers of orphaned children (Desmond, 2002).

The emotional trauma that families go through due to losing family members means they need psycho-social support in helping them to cope with the loss (Cohen, 2000). This also helps orphans to deal with orphan hood more easily.

This involves what type of care a child receives after the death of its parents. This calls for the skills of psycho-social support to help families cope easily and is an ongoing process of meeting the physical, emotional, social and mental needs of orphans. Extended families experience problems in caring for orphaned children outlined as follows:

2.3.2.1. Emotional impact

According to Webb and Paquette (2000), the emotional suffering of children when parents become sick and die may be neither recognised nor responded to. Children often become withdrawn and some will show antisocial behaviour for which they are likely to be punished. Particularly in societies and cultures that devalue children's needs and rights, children are more likely to internalise their pain. They should be given opportunity to express their feelings and explore their fears and anxieties. Many children blame themselves when problems occur (Department of Social Development, 2002).

Young children in particular may feel that a parent has become ill, died and left them because they had been bad, and the parent no longer loved them or is punishing them (UNAIDS,2001). Children whose parents are living with HIV often experience many negative changes in their lives and can start to suffer neglect, including emotional neglect, long before they are orphaned. Eventually, they suffer the death of their parent(s) and the emotional trauma that results. They may then have to adjust to a new situation, with little or no support, and may suffer exploitation and abuse (Department of Social Development, 2002).

In one study carried out in rural Uganda, high levels of psychological distress were found in children who had been orphaned by AIDS. Anxiety, depression and anger were found to be more common among AIDS orphans than other children. 12% of AIDS orphans affirmed that they wished they were dead, compared to 3% of other children interviewed. These psychological problems can become more severe if a child is forced to separate from their siblings upon

becoming orphaned (Webb, 2000).

It is widely accepted, based on experience in South Africa and the rest of the continent, that the best models of care for vulnerable and orphaned children are found within the children's communities, not in institutions. According to the Department of Social development (2002) orphans cope better if they remain in familiar surroundings, in family units even if not their biological families. If extended family network and communities are to continue to play this role, it is essential they receive social and material support from government, development agencies and the private sector.

2.3.2.2. **Household impact**

The loss of a parent to AIDS can have serious consequences for a child's access to basic necessities such as shelter, food, clothing, health and education. Orphans are more likely than non-orphans to live in large, female-headed households where more people are dependent on fewer income earners (Desmond & Gow, 2001). This lack of income puts extra pressure on AIDS orphans to contribute financially to the household, in some cases driving them to the streets to work, beg or seek food (Steinberg, 2002).

Jackson (2002) identified a trend that children whose parents die of AIDS in towns are usually taken back to the rural areas. They have to adapt to loss of parent(s) as well as to rural life. The security and stability of their family is disrupted and there is no social safety net or mechanism to help children through this transition period. Education ceases, thereby increasing risk behavior among the older orphans especially girls. If both parents have died, the orphans are dispersed to various relatives. The disintegration of the family often means the children may not grow up in a family and will not receive attention and guidance from relatives. Grandparents might find it difficult to discipline and control these children. In some cases, some orphans may run away from home or from the extended family home to escape poverty that AIDS- afflicted and affected families are subjected to. Some children might be sent to a town or abroad to

make up for the loss on income and help support younger siblings.

2.3.2.3. Education

Children orphaned by AIDS may miss out on school enrolment, have their schooling interrupted or perform poorly in school as a result of their situation (Jackson, 2002). Expenses such as school fees and school uniforms present major barriers, since many orphans' caregivers cannot afford these costs. Extended families sometimes see school fees as a major factor in deciding not to take on additional children orphaned by AIDS (Desmond & Gow, 2001). Even before the death of a parent, children may miss out on educational opportunities. Research in Kenya suggests that children of HIV-positive parents are significantly less likely to attend school than other children (Chege, Mavimbela & Vermaak, 2004).

Outside of school, AIDS orphans may also miss out on valuable life-skills (Department of Social Development, 2002) and practical knowledge that would have been passed on to them by their parents. Without this knowledge and a basic school education, children may be more likely to face social, economic and health problems as they grow up (Desmond & Gow, 2001).

2.3.2.4. Stigmatisation

Children grieving for dying or dead parents are often stigmatised by society through association with AIDS (Jackson, 2002). The distress and social isolation experienced by these children, both before and after the death of their parent(s), is strongly exacerbated by the shame, fear, and rejection that often surrounds people affected by HIV and AIDS (Jackson, 2002). Because of this stigma, children may be denied access to schooling and health care. Once a parent dies children may also be denied their inheritance and property (Chege, Mavimbela & Vermaak, 2004); (Desmond &Gow, 2001). Often children who have lost their parents to AIDS are assumed to be HIV positive themselves, adding to the

likelihood that they will face discrimination and damaging their future prospects. Sometimes this occurs because it is assumed that they are infected with HIV and their illnesses are untreatable (Desmond & Gow, 2001).

2.3.2.5. Family structures

In African countries that have already suffered long, severe epidemics, AIDS is generating orphans so quickly that family structures can no longer cope (Jackson, 2002). Traditional safety nets are unraveling as increasing numbers of adults die from HIV-related illnesses. Families and communities can barely fend for themselves, let alone take care of orphans. People with HIV develop AIDS and die, leaving behind a generation of children to be raised by their grandparents, other adult relatives or left on their own in child-headed households.

According to Moyo (2001), traditional systems of taking care of children who lose their parents, for whatever reason, have been in place throughout Sub-Saharan Africa for generations. But HIV and AIDS are eroding such practices by creating larger numbers of orphans than have ever been known before. The demand for care and support is simply overwhelming in many areas. HIV reduces the caring capacity of families and communities by deepening poverty, through medical and funeral costs as well as the loss of labour (Steinberg, 2002). Early identification of vulnerable children; succession planning; facilitating kinship and community foster care; assistance with social grant applications, counseling and psycho-social support are all essential components of a community- based strategy.

2.4. CONCLUSION

It is clear that AIDS is having a devastating impact on South Africa. There are many possible reasons why South Africa has been so badly affected by AIDS, including poverty, social instability and a lack of government action. One way to gain a better insight into the situation is to look back on the history of AIDS in

South Africa.

It is difficult to overstate the suffering that HIV has caused in South Africa. With statistics showing that almost one in five adults is infected, HIV is widespread in a sense that can be difficult to imagine for those living in less-affected countries. For each person living with HIV, in South Africa and elsewhere, not only does it impact on their lives, but also those of their families, friends and wider communities. Apart from the death and suffering that HIV has caused on an individual, family and community level, South Africa's AIDS epidemic has also had a substantial impact on the country's overall social and economic progress (UNICEF, 2006).

The orphan crisis is impoverishing even working households, where caregivers lack sufficient resources to provide basic needs. The studies indicate that Extended family networks play an important role in the care of orphans and vulnerable children (Jackson, 2002). Many of these families live in extreme poverty as a result, care givers need help from external sources to ensure that the developmental needs of children are met and maintained. According to the Department of Social Development guidelines on children affected by Aids (2002), children should as far as possible, remain in their homes or communities of origin to avoid further trauma related to loss of parents. Family capacity building and access to a variety of appropriate resources and support should be primary concern to service providers.

The family is the cornerstone of African society, so families should be at the heart of HIV/Aids interventions. Programs (developed by different service providers) should seek to strengthen the affected family units and its ability to cope with added strains that HIV/Aids inflict. Programs should provide opportunities for families to remain productive without creating distinction or exacerbating further possible stigma. Provision of training for family life skills and opportunities for development should be made available for extended families caring for HIV/Aids orphans. Support offered to those families may be utilised to improve quality of

life (Department of Social Development guidelines on children affected by Aids, 2002).

The Aids epidemic has had far reaching effects on families. Many of the most striking images of the HIV epidemic are of families especially: grandparents surrounded by grandchildren (Desmond & Gow, 2001). When both parents die, most surviving children, in the majority of cases, are then taken care of by their grandparents and, more particularly, their grandmothers.

Furthermore most of the grandmother households are caring for relatively large numbers of orphans compared to the size of other households. This is because grandmothers may inherit children from several households, from several of their children (Jackson, 2002).

Extended families caring for Aids orphans experience multiple and acute difficulties. These are likely to include severe financial hardship; malnutrition; neglect; ill-treatment, dropping out of school; lack of food, clothing and blankets; and inability to obtain birth certificates. Many will also experience stigma and discrimination.

CHAPTER 3

RESEARCH METHODOLOGY

3.1. INTRODUCTION

The extended families caring for orphaned children whose parents passed away due to HIV/Aids were analysed. Focus was on the needs and problems of these families, their assets and coping mechanisms as well as how these extended families use the resources available to them to address challenges they faced (Cohen, 2000).

3.2. RESEARCH APPROACH AND DESIGN

For the purpose of this research project, the researcher chose to employ a predominantly qualitative approach. According to Hahn (2002), qualitative research is described as the systematic study of data so that its meaning, structure relationships and origins are understood. He further describes it as the process of looking at and summarising data with the intent to extract useful information and develop conclusions. This involves analysis of non- numerical data, in this study words and observations. This research design is an open design to accommodate participants' opinions at every stage of the investigation with focus on participants' perceptions and experiences (De Vos, 1998).

According to Denzin (1998, 2000), qualitative research is a multi perspective approach to social interaction which aims at describing, making sense of, interpreting or reconstructing this interaction in terms of the meanings that are subjected to it. This type of research is regarded as a form of inquiry that explores phenomena in their natural settings. He further perceives qualitative research as a method aimed at analysing concrete cases, starting from people's expressions and activities in their local contexts.

The research design used in this study is classified by De Vos (2005) as exploratory, as it seeks to describe a particular phenomenon thoroughly, with the aim of developing ideas and theoretical generalisations.

According to Mouton (1998), the purpose of exploratory research is to gain insight into a situation, phenomenon, community or a person. Exploratory research relies on a particular form of data collection viz. observation, questionnaires and interviews (De Vos, 2005). Cooper and Schindler (2001) indicated that explorative research seeks to explore the perceptions and interpretations of lived experiences of a specific phenomenon. They further stated that, since this kind of research employ interviews, observations and field notes as methods of data collection, the perceptions of the respondents were clarified and thus enhance better understanding.

3.3. THE RESEARCH QUESTION

The following research question was formulated: What are the challenges faced by extended families caring for HIV/Aids orphans?

3.4. GOAL OF THE STUDY

Based on the motivation, problem statement and research question, the goal of this study was to conduct an analysis of extended families affected by HIV and Aids taking care of orphans, living in the Kyasands informal settlement so that service delivery could be improved.

3.5. OBJECTIVES OF THE STUDY

- To explore the problems and needs of extended families living with HIV/AIDS orphans in Kyasands informal settlement, in terms of social, emotional and material aspects.

- To conduct an analysis of the assets of extended families affected by HIV/Aids.
- Determine how households respond to the needs and challenges they face.
- Make recommendations in terms of improving service delivery in Kyasands.

3.6. SAMPLING PROCEDURE

3.6.1. Population

The total set of people in a research study is referred to as the population. Mark (1996) defines population as the collection of all individuals, families, groups, organisations, communities and events that the researcher is interested in finding out more about. This study aimed at exploring the challenges faced by HIV and Aids affected families from Kyasands informal settlement, who form part of the workload of Witkoppen clinic. The population of this study consisted of those families who lost family members due to HIV and Aids and where there were orphaned children involved. Respondents were extended families which included grand parents, uncles and aunts.

3.6.2. Sampling strategy

Sampling involves obtaining a population in which data will be collected by means of interviewing, observation and documentation (Mouton *et al.*, 1998). Mouton further explains a sample as a process of selecting a small group of people from a defined population. A purposive sampling was used on those extended families affected by HIV and Aids caring for Aids orphans. This type of research was based entirely on the judgment of the researcher in choosing respondents (De Vos, 2005).

The researcher employed a non-probability sampling strategy which included

convenience or availability samples (Babbie, 2003). This type of sampling allowed the researcher to select the sample on the basis of his or her own knowledge of the population, its elements and the nature of the research aims. This enabled the researcher to interview only those who were willing to partake in the research project. According to Creswell (1998) the purposeful selection of participants represents a key decision point in a qualitative research. Creswell continues to indicate that judgmental sampling is the type of sampling that involves the conscious selection by the researcher of certain participants to include in the study and proceeds on the belief that the researcher knows enough about the population and its elements to handpick the sample.

Sampling was conducted according to the following criteria:

- willing participation,
- only African people who are extended families caring for Aids orphans,
- staying in Kyasands Informal Settlement,
- Who visited the Witkoppen Clinic for assistance.

The reason behind selecting African race was because the Kyasands community consists mainly of African race. Availability non-probability sampling was chosen on the basis of the researcher's knowledge of HIV and Aids patients who visited Witkoppen Clinic from Kyasands Informal Settlement.

3.7. DATA COLLECTION METHOD

According to De Vos, Fouche and Delport (2002), data collection is a process of discovery and is influenced by the way in which the researcher views the world. They further state that it is essential for an accumulation of information with a view to gaining answers to the research question.

In this study, the interview method was used with the aim of providing the

respondents with the opportunity to speak and construct their reality with the purpose of obtaining deeper insight into issues relating to the survey project. Semi- structured interviews (See semi-structured interview schedule in Appendix B) were utilised to create a frank, open and interactive mode. Through these interviews, respondents were provided room to develop their own concerns and answer questions freely. The researcher planned to use a tape recorder to record data, but that was not possible. Two respondents withdrew their consent to be interviewed due to the introduction of the tape recorder; as a result the interviews were conducted with 18 respondents caring for HIV/Aids orphans. The two who withdrew indicated that confidentiality that was promised was now broken because people might be able to identify their voices. They complained and indicated that the researcher tricked them and as a result they lost interest.

Due to this experience, the researcher, because of the fear of losing more of the respondents from her sample, then decided to involve her colleague to assist her in data collection. She explained everything to her, the objectives of the study, what she was hoping to achieve as well as the role that her colleague was going to play and how to do it. In short the researcher trained her colleague to assist her with data collection by asking questions.

The respondents were interviewed at their own homes in Kyasands informal settlements. Semi-structured interviews were conducted with a fairly open framework which allowed focused conversational two way communication. There were more general questions or topics to allow flexibility to probe for details or discuss issues which were not known. The interview was less intrusive to those being interviewed as the semi-structured interview encourages two-way communication.

Often the information obtained from semi- structured interviews provides not just answers but explanations. It is necessary to assure in personal interviews that the person interviewed understands and trusts that the response will be

confidential. The researcher facilitated the research and was assisted by her colleague in asking questions. The procedure was explained to the individuals during interviews. The researcher made sure that respondents understood what was required of them. After each question was asked, field notes were taken about the interview situation. This meant the researcher had a major task in making accurate and systematic notes during the interview sessions.

3.7.1. Procedure followed in data collection

The respondents were approached on individual basis using semi structured questionnaires. After arriving at the interview site, the researcher introduced herself and the colleague and the procedure to be followed as well as obtaining consent from the respondent to participate in the study (Creswell, 1998). A consent letter was given to respondents to sign before the interview and it was read to those who could not read or write and they gave verbal consent to participate in the study (see Appendix A). The researcher's colleague assisted with facilitation of the interviews by asking questions and writing notes and the researcher also personally wrote down as much as possible while taking field notes. This was so that she could personally note everything as said by the respondents for the purpose of analysis.

The central question asked was: *Tell me about the challenges you face in caring for the Aids orphan*. The interview was practical and covered the most useful information relating to the research questions (see Appendix B – Interview schedule). The interviews were conducted with a single participant at a time. The interview was conducted, with the participant doing the talking and the researcher doing the listening, observing and taking notes (Babbie & Mouton, 2002). The researcher followed and adhered to all ethical measures previously explained. The facilitator used communication skills such as minimal verbal responses, paraphrasing, clarification, and listening, as well as interviewing techniques and tips (De Vos *et al.,* 2002).

3.8 PILOT STUDY

The researcher used a pilot study in which she orientated herself to the research study. She ensured that the procedures were suitable, valid, reliable, effective and free from problems and errors, and that possible precautions were made to avoid any problems that might arise during the study. Results of the pilot study were used to refine and/or to make adjustments necessary in the research tool. Only when the researcher had confidence in the design, methodology, interviewing skill, and knew her role as the researcher, did she proceed with the research study.

3.9. STEPS IN DATA ANALYSIS

According to Mouton (1998), the term analysis means the resolution of a complex whole into its parts. The data to be analysed came from interviews and field notes. Babbie (2001) refers to qualitative analysis as methods for examining social research data without converting them to a numerical format. In this study, a qualitative approach to data analysis was conducted with field notes and interview data.

The tradition followed in this study was content analysis where the researcher read the entire interview and identified several topics in the interview. These topics then became primary categories or category labels. Once the categories had enough data, the researcher chose to categorise this data into sub-categories of two or more. When each category was reasonably full and saturation was reached (that is no new data emerged), then the researcher wrote descriptive paragraphs about categories and looked for relationships between them. The raw data was coded using open coding. Data was sorted into categories, themes and ideas (Denzin & Lincoln, 1998). The categories were compared with each other for similarities and differences (Strauss & Corbin, 1998). When differences were found, a new category was added resulting in

open codes. Generally open coding is repetitious as coding categories are added, combined and revised until the coding categories do not require further modification. After open coding axial coding was used. During axial coding, categories were related to their sub-categories to form more precise and complete explanations about phenomena (Strauss & Corbin, 1998). In axial coding, categories and sub-categories were examined to see if they were linked or related to one another. Collected data was manipulated for the purpose of drawing conclusions that reflected on the interests, ideas and theories that influenced this study.

The coding process was initially started with preassigned categories based on general overall intent of the study, for example: what is the general experience of caring for an HIV/Aids orphan, and what are the challenges thereof. (See Appendix C for a list of preassigned categories). The focus was on having a general idea as to whether or not and if so to what depth the study was able to capture information with the research questions. This provided insight into data as themes emerged in the context of broad categories.

3.10. TRUSTWORTHINESS

Trustworthiness is establishing validity and reliability of qualitative research. The qualitative research is trustworthy when it accurately represents the experience of the study participants. Trustworthiness of data is demonstrated through the researcher's attention to and confirmation of information discovery. The goal of the research was to accurately represent the study participants' experiences (Streubert & Carpenter, 1999:28). Four criteria used to measure trustworthiness of data included the following: credibility, dependability, transferability and confirmability. For purposes of this study the researcher chose to apply credibility which is demonstrated when respondents recognise the reported research findings as their own experiences (Streubert & Carpenter, 1999:330). According to Lincoln and Guba (1985) activities increasing the probability that credible

findings will be produced include member checking as a technique chosen in this study to establish credibility.

Member checking was conducted with seven respondents to confirm the findings of the study (Cresswell, 1998, 2003). The data, categories, interpretations and conclusions in this study were tested with members of the research sample from whom the data was originally collected. Information was submitted to study respondents which assisted in ensuring that all the information was relevant. Seven respondents contacted checked the answers provided on the questionnaire and the findings by the researcher and confirmed it was a true reflection of what they said. Some additions were made and the respondents confirmed the contents. This was easy to conduct because during the initial interviews, a rapport with respondents was established (Moore & Spiers, 2002), which enabled researcher to establish credibility of findings.

3.11. LIMITATIONS OF THE STUDY

Most of the respondents were Zulus and the interviews being done in Zulu then interpreted into English could result in the statements losing connotation or a respondent being misunderstood because some Zulu words lose meaning when translated to the English language and this could not be avoided.

The researcher is employed on a full time basis and time was one of the limitations as well as transport expenses. Informal settlements have poor roads and this was one big problem to the researcher who had to walk long distances within the settlement to reach her respondents which caused most of the time to be lost.

3.12. CONCLUSION

In this chapter the research methodology was discussed in more detail. The respondents in this study were from Kyasands informal settlement. They were

selected using the researcher's own judgment. To confirm trustworthiness, the researcher involved the respondents to confirm data collected, which is member-checking. The implementation of the methods led the researcher to obtain data which is presented and analysed in the next chapter of this study.

CHAPTER 4

PRESENTATION OF FINDINGS

4.1. INTRODUCTION

Respondents in this study were residents of Kyasands informal settlement, situated North of Johannesburg. In each family, one respondent, the breadwinner or family head was interviewed. This includes persons responsible for daily decision- making of the family, buying of food or taking care of children. The interview was used to explore to what extent they cope with the challenges they face, what assets they possess and what kind of support and assistance they receive from service providers. Several specific areas of their experiences emerged from the data which included problems caused by the very orphans they care for, challenges caused by stigma, increased family expenses, changed family structures and challenges caused by shortage of space, needs and assets. Categories and sub-categories of this study are summarised in the table (4.1) below and will accordingly be discussed.

Table 4.1: Summary of findings

Categories	**Sub-categories**
Assets/Resources	1. Social capital 2. Physical capital 3. Financial capital
Challenges	1. Stability in homes 2. Family Structure 3. Children behaviour change due to grief 4. Stigmatization 5. Increased Family expenses

Needs	1. Material assistance 2. Legal documents 3. Housing 4. Emotional Support
Service Rendering	1. Social grants 2. Material assistance 3. Professional support 4. Training

4.2. KEY FINDINGS

4.2.1. ASSETS/RESOURCES

In this section, attention was paid to composition and strength of assets and resources and their use in family activities to make a living. Every family irrespective of their poverty status possesses assets that allow them to adjust to shocks in life (Carney, 1998). These assets essential to their livelihoods are as follows: human, financial, natural, social and physical capital (Patel, 2005). Respondents in this study do not possess all assets; their human and natural resources base were very weak. Three assets had direct implications for the use of different sources of extended families namely: social, physical and financial capital, of which their relative strength lies in their social capital. They do not own much but have enough support systems especially from their relationships.

4.2.1.1. Social capital

According to Carney (1998) social capital includes social networks and relationships of trust such as family, neighbours, friends, kinship networks and

associations. This includes the ability to call on friends or neighbours in times of need. Families support each other in terms of caring for orphaned children. The extended families had an opportunity of caring for the biological parents before they died of Aids and now they continue to care for the orphaned children. These children knew them before their parents' deaths.

The social capital operating through their relationships is critical to their ability to recover from the loss of their family members. Their social capital linkages include their relationships with each other and to formal and informal community organisations like support groups where they get an opportunity to share their difficulties and experiences and receive support either materially or emotionally. The following respondent shared her experience as follows:

My perception of life changed a lot since I started attending the foster care parents' support group at the clinic. We talk about our problems, share our difficulties and help each other on how to approach situations in terms of caring for orphaned children. I will not stop attending this group because I gained a lot of information from there as well as emotional support because I struggled to accept the loss of my only daughter.

Due to loss and challenges of caring for orphaned children, care givers need support apart from the professional assistance they get from service providers. In this case, social resources provided this respondent with what she needed to survive. She received information and emotional support from the social network available in her community. The support group assisted the respondent to notice that she was not the only one with problems and it was possible to live after the loss of a family member.

Another perception from another respondent is as follows:

Our Pastor is a true man of God. He is so supportive to our family. Since the death of my sister he has never stopped to support our family socially, spiritually and materially. All families with orphaned children receive some food parcels from the church every month

end. There are some people who also volunteered to pay for these children's school fees from our church. This is so great.

The church institution is playing a very crucial role in the lives of the extended families. This family is receiving spiritual upliftment and support from the church members which gives them reason to continue with their lives. Within communities the social networks are still respected and are the ones which still give them hope. Extended families draw their support primarily from family, neighbours, community institutions and informal institutions (Jackson, Mutangadura and Mukurazita, 1999). Thus the social capital of families operating through their relationships with families and community is critical to their ability to recover from death and grief of a family member due to HIV/Aids. Due to stigma and rejection, some families did not get any help from their neighbours but from the service providers like their churches and the support groups they belonged to.

4.2.1.2. Physical capital

This type of asset involves the sense of ownership by families. It includes tangible goods and resources that families call upon to achieve their objectives (Patel, 2005). In terms of the respondents in this study this involves the following: their shacks, furniture, tools and some equipment like radios they own. Most of them own shacks made of corrugated iron sheets. Each family had battery operated radios; some owned black and white television using solar systems since the area does not have any electricity. Families share their shacks with orphaned children they care for as their support systems. The statement from one respondent regarding her experience is as follows:

I have been living in this shack for the past fourteen years. We do not have electricity that is why I use the solar system for my TV. I have a radio using car battery to listen to news.

The TV uses more power that is why I prefer to listen to the radio during the day. We will be moving to the RDP houses in Cosmo City very soon where we would be able to watch TV all day because there will be electricity.

Mrs Mooi (*assumed name*) owns a shack, a radio and television. She has a sense of ownership that gives her pride as a person and she values them as she can be informed through the systems she owns. She has some hope to own an RDP house made of bricks they were promised in Cosmo City. Another respondent expressed her experience as follows:

I sleep on the sponge bed in my room and all these children have to spread themselves on the floor during the night in another room. We sit around this table for our dinner and that is very crucial time for our family because we take that time as time to fellowship with each other.

The respondent's living arrangement allows her to have quality time with her family. She owns a spacious shack which is able to accommodate her and her grandchildren. She owns a sponge bed and comfortable dining table. The family spends quality time with each other. This family has time to discuss their issues together during dinner around the table which most of the family's lack. The majority of shacks families own differ in quality and size. The shacks were maintained and kept very clean and neat to show how much they value them.

4.2.1.3. Financial capital

Financial capital can be in the form of cash savings or remittances. Some extended families secured casual employment and receive income to care for their families. Since the extended families are caring for orphaned children, they depend on foster care and child support grants for survival. The old grandparents also depend on old age pensions to maintain their families. Here is one of the

responses in terms of financial resources:

Every cent I get from my two-day part time job, I make sure to use it appropriately. The shack we stay in belonged to their mother and the material was bought by her employers before she died. I have applied for the foster care grant and looking forward to the approval of my application in order to augment my two day salary.

The Mandla family depends on her two day salary that Mrs Mandla is receiving from her two day domestic work. Beside the meager income, Mrs Mandla makes sure she uses it to meet the needs of her family. Families depend on their assets for survival (Carney, 1998). This family is awaiting approval of the foster care grant to improve their financial status.

The following respondent shared her life experience as follows:

We are having a stockvel in our area consisting of fifteen women. We contribute some money every month which we share at the end of every six months. What happens is, we take the money to the post office. After six months we go and withdraw a certain amount and we buy grocery in bulk and share it. This is assisting me a lot and we never struggle in terms of food. I struggle with other things with the foster care grant I receive for my nephew. I also use part of this grant to contribute to our burial society in case crisis happened.

Mrs Leeto found a way to save money in order to meet her family needs. Due to this stockvel, she manages to meet her family's basic need for food and uses the grant money for other family responsibilities. Mrs Leeto also prepared for her time of bereavement by contributing to the burial society. This is an indication that this respondent knows how to spend her money wisely which enables her to care for her family.

4.2.2. CHALLENGES

Challenges are issues or obstacles which make it difficult to achieve desired goals, objectives or purpose in life. Extended families caring for HIV/Aids orphans are faced with challenges in terms of caring for these children. The problems differ from personal up to caring for these particular orphaned children. The challenges differ from being emotional, financial or social. They are outlined and categorised as follows:

4.2.2.1. Stability in homes

Stability within the family in the study includes the ability of the family to stick together even during hard times. In this case, families are having the ability to stay together after losing members to death. Children are not expected to move from one place or family to another. According to the findings, experiences of extended family members differ depending on the relationship they had with orphaned children. For some they have been staying with orphaned children even before their parents died of Aids and they continue to live together. Here is an example of one of the respondent's experiences in caring for an orphaned child:

I love my granddaughter and am happy to spend time with her. You do not know how much I struggled to look after her parents. Firstly it was her father who died four years ago. Last year I had to look after her mother. Now she is my responsibility, I have to make sure I meet all her needs no matter what. She is my only grandchild; her father was my only child. So she is all I have.

In this case this child Mangy, does not have to adjust to new ways of living, she is staying with her grandmother Gloria whom she knew and stayed with even before the death of her own parents. There is no need for Mangy to stay with someone she does not know. Orphaned children staying with their extended

families help them to stay part of the community and family they are familiar with than being taken to orphanages or institutions. Extended families (in particular grandmothers), seem to take over the parenting role with multiple grandchildren (Mutangadura, 2000). In this study, Grandmother Gloria had an experience of taking care of the biological parents before they died which indicates how stable this family remained even after loss.

Here is a different situation of a family stability affected by the death of parents.

It was after my sister's death that we sat together as a family and shared the responsibility to care for her children. She had four children from different fathers. I took these two boys because their father is dead and the other two boys were taken to their fathers. It was hard to separate these boys but anyway they will visit each other when they grow up. I could not afford to take care of all of them is too demanding.

Due to loss of parents to death, children were separated to stay with a relative and others taken to stay with their biological fathers. This kind of arrangement might have effects on the behaviour of children since they were forced by circumstances to be separated and leave their mother's house. They were not even consulted they were told to leave and stay in different places and their family stability was broken by death.

According to Allen (1999), a stable family is important to child behaviour and development. Family transition or breakups due to death causes increases in children behaviour problems. The presence of HIV/Aids in families entails a variety of forms of instability and thus contributes to unstable and degrading living conditions for family members. Within a family when parents die, it has a devastating effect on the capacity of families to remain intact. USAID (2004) reports indicate that orphans adjust easily if they remain in familiar surroundings, in family units they know.

4.2.2.2. Family structure

The composition of a household plays a crucial role in the survival of a family. Families which have been struggling to make ends meet are forced to accommodate extra members within their household which changes their way of living. It increases their expenses and changes their quality of life which includes the quality of food they eat. One respondent shared her experience of caring for an orphan as follows:

It is painful to watch my nephews like this. They are used to city life now they have to adjust to our informal settlement lifestyle and share a shack with us. This is the change they have to adjust to because there is nothing I can do. I can see how hard they try to make things easier for me. They never complain about anything, but I think my sister has to take them because I have my own six children plus the two of them it is too much for me and my wife is starting to complain, but that is not the point. The accommodation is not enough for us all.

This family is struggling to make a living, with insufficient accommodation but now they have to accommodate two extra family members which affects their way of living. The two orphaned children used to have privacy in their parents' home, but now they have to inconvenience their uncle's family in a shack. These children understand the circumstances only the care giver is concerned about them and to save his marriage. This is an indication that extended family members experience problems personally and with orphaned children which affects their lives due to changing family structures.

In this case the children are forced to adjust to new environments and lifestyle. The extended family support network functions through changes in household composition, with orphans moving out into one or more relatives' households (Caldwell, 1998). Extended Families cope with relatives' deaths by ensuring that children affected by HIV/Aids receive care from a substitute caregiver. Here is

another example of a changed family structure:

When my first daughter died, her in-laws agreed to bring her two sons to me because their son needed to marry again, but unfortunately he died a year later. The previous year my own sister died as well and she left three boys in my care. I have to take care of extra five children including the expenses they come with. I have to get an alternative spacious place to stay.

In this case the family has problems with space. The family structure changed completely as the respondent has to accommodate and care for five extra family members. She lives in a small shack yet on top of that she has to accommodate extra family members. Her family structure changed completely and added extra expenses for her. According to Chege and Vermaak (2004), HIV/Aids changes family structures and functions which includes changes in household size. Increase in numbers affects household spending due to additional members in the family (UNDP, 2000).

4.2.2.3. Children behaviour change due to grief

There was a clear indication that most of the children and the care givers were still grieving the loss of their family members. Some of the children showed signs of anti social behaviour which also affected those caring for them. There were some children who were disrespectful to their care givers which was affecting their relationship. Some of the children deal with the loss in a different way which may affect their care givers. A statement from respondent showing signs of grief is as follows:

I am so worried about this boy. His brother is much better. This one has changed a lot. He likes indoor life and avoids talking to people. Sometimes I get very worried about this behaviour because he is supposed to be playing with other children. He regards his cousins as his only friends. Instead of playing with other children you will either find him

sleeping or just sitting quietly in the house, I am scared of what he is thinking about. It is not normal for a child to be alone and think like this.

The findings indicate that children respond differently to situations and they (situations) also affect them in different ways. The child (Mandla) in this case decided to isolate himself from other people and be alone which also affects his aunt Maria. Maria has to focus on him (Mandla) and that might as well affect other children who also need her attention. When a family member dies, children react differently due to the loss (Jackson, 2002). They often withdraw from their social activities and spend more time by themselves. Following loss is grief which is part of both pain but also of healing (Kubler-Ross, 2005). To go through grief one needs a strong support system to make a tremendous difference in the healing process. Logan (2005) indicated that most of the children remain at the first stage of grieving which is isolation just like Mandla in the above mentioned statement.

Logan (2005) further indicated that some children manage to move from the first stage and remain in the second stage which is anger. Children may be angry at themselves for the loss that took place. They are angry at the loved ones who died for letting it happen and are sometimes just plain angry at the world. They function at emotional level. Hereunder is a child who is stuck at the second stage of grief:

My problem with this child is that he is now too much. He never listens when adults talk to him. He is always angry at everyone. Even his teachers complain that he is always involved in fights at school. Anyway, he was not like this when his parents were alive. He is now associating himself with wrong children. He is stubborn, smokes dagga all in a short space of time. The psychologist said that I must bear with him but I think he is taking advantage of me. I used to smack him but now he is tall I cannot do that anymore. How long am I supposed to bear with him? This is too much!

Dealing with grief affected the above child who is always aggressive towards

other people including teachers and other pupils at school. If the school expels him, this will have impact on his future and this calls for professional intervention. The behaviour of the child is also affecting his caregiver.

This statement is also confirmed by Webb, (2000) when he states that, the emotional suffering of children due to change, when parents become sick and die may be neither recognised nor responded to. Children often become withdrawn and some will show antisocial behaviour for which they are likely to be punished. This study confirmed this research because this child was found to be having anti social behaviours like being aggressive towards his care giver and other children. The care giver consulted the psychologist but now the behaviour of the child still continues, which means it needs a follow up session.

There are children who pass through the stages of grief up to the fourth stage which is depression. According to Logan (2005) depressed children develop and entertain thoughts of suicide, here is a comment from one respondent about a child who attempted suicide because he could not cope with the loss of his parents and adjusting to new environment at the informal settlement:

I am personally depressed especially if I think of this child. We always have to be on guard. Last year he attempted suicide complaining that because there is no solution to his problem and I cannot afford to take him to his previous school where he has friends, he better die because at the informal settlement is just like if he is dead. There is no life at all for him. He always wanted money to go to cinema but I cannot afford. The thing is now I spend money on him and tend to ignore my own children. I really don't know what to do. He cannot even notice how hard I try to make him happy.

According to the findings, this child is used to urban life and could not adjust to life at the informal settlement where there are no resources like entertainment for youth as well as schools. He had no friends and decided to kill himself because he could not cope with new ways of life. The care giver tried her best to make this child happy but he could not appreciate it. Due to this, tension was

experienced in this family because now other children felt neglected. This is an indication that some extended families feel trapped by their circumstances and are personally forced to cope with new ways of living. They are forced to have undivided attention to both orphaned children they care for and their own children in order to have a balanced family life.

In conclusion, due to grief in this study, some of the children developed attitudes which included being stubborn, crying all the time, they isolate themselves and not talk to other people, and their school performance dropped. Some of the children develop behavior problems and lose respect for their care givers. They develop some behaviour that needs professional intervention hence others took them to social workers for counseling and psychologists for assessment.

4.2.2.4. Stigmatisation

Some extended families staying with HIV/Aids orphans are stigmatised and ostracised. Unlike other chronic / terminal illnesses, HIV/Aids infection is further complicated by the stigma related to the transmission. Due to disclosure fears and stigma associated with this pandemic, many families isolated themselves and their children in fear of maltreatment. Thus, they are cut off from valuable support. Isolation places them and their family members at risk for mental health disorders (e.g. depression, and anxiety). A statement from one victim of stigmatisation is as follows:

My grand child is suffering. Even myself, I cannot say I have accepted the death of my daughter; I still miss her a lot. What makes this more difficult is the fact that my neighbours are isolating us. They call my grandchild names due to the fact that her mother was killed by Aids. They do not want her to play with their children saying she will infect them. This is a very difficult situation because you always think and suspect that people are talking about you. Our neighbors, since my daughter came home until her

death they never visited us. There are some people who think we are filthy and God is punishing us, they do not even want to speak to us. This is very painful. I always miss my daughter when I see my grandchild but she is my comforter. I will take good care of her, no matter what.

Due to the HIV stigma this family is lacking support from its neighbours. Life changed for them after the loss of their family member due to Aids. This shows that there is still a stigma attached to this pandemic and it will take time for people to understand and accept those affected families especially those caring for Aids orphans. Some of the families are still struggling to deal with the loss of the family member and they are isolated within the community in which they live due to the HIV stigma. Families suffer rejection and this on the other hand prolongs the period of grieving for families who lost their loved ones. They do not only have to deal with their own grief and emotional suffering, but this is made worse by the way their community treats them. Talking about it will lower the stigma families feel. The stigma also hinders families to benefit from services rendered within communities and usually results in loss of respect within the community (UNAIDS, 2004).

The stigma associated with HIV/Aids has been reported to be one of the factors that contribute to the depletion of social capital. Fear of contamination and ascription of guilt to afflicted individuals results in breakage of social networks and increased social exclusion (Robinson, 2000).Social capital can be severely strained and that affects people's way of making a living.

4.2.2.5. Increased Family expenses

Most of the families are not coping financially in terms of caring for Aids orphans because they cannot afford to meet their needs. A majority of these families live under poverty. The financial difficulty is the main reason which leads to poverty.

There are limited resources to meet children's basic needs especially those caring for HIV positive orphans. Challenges families face include medical care and inability to afford good diet for them. A need for finance is caused by a decline in household income due to loss of family members and results in increased household expenditure in terms of transport, food, clothes, and school fees. Access to credit is also restricted due to unstable sources of income. Here is one of the personal expressions of a respondent as follows:

I am experiencing some financial difficulties since I took this child into my house. I am a labourer and the money I received used to be enough for me and my children. Not to say I don't want this girl, but I just want to show how I am struggling to make ends meet. If I can get an extra source of income, our problems will be limited. The expenses include her medical expenses. Yes we do not pay for them but to collect them we have to pay transport to town since we do not have any hospital nearby offering Art's for children. We can only get them from the hospital in town. I hope application for her disability grant will be processed soon it will help me to take her to follow up and collect her treatment on time. I will also be able to buy a suitable diet for her.

This is an indication that large proportions of extended families caring for orphans depend on government grants for survival. This respondent cannot afford transport to take the child to hospital; she is relying on the application for a grant that she made. The study indicates that the socio-economic status of families was generally low which may partly be due to the informal settlement selectivity of the sample. Most of the families depended on social security assistance for survival or doing casual jobs as sources of income, either part time or full time (Kayombo, 2002). Financial difficulties are a common problem to them and it leads to poverty. Loss and shortage of income, rising expenditure and the need for adjustment of household management systems may produce internal tension and conflict (Kabir *et al*., 2000) because care givers try by all means to make orphans happy and neglect their own children. As part of the coping mechanism, some extended families are involved in income generating project

activities within their community offered by different NGOs, CBOs and FBOs. They learn to develop skills in order to make a living like the following respondent:

The Methodist church in our area sent some people to teach us some skills. I have learnt to make candles. At least I get some cash from sales because there is no electricity in our area; most of the people buy candles from us. We are a group of four grand mothers operating from the church container here in the settlement. We can buy food and pay for children's school transport and put food on the table. This has made a difference in our lives.

According to this respondent, they are not waiting for help to come to them but they devised some means to make a living. They did not give in to their circumstances, but they got empowered and responded positively to services rendered to them.

4.2.3. NEEDS

Many aids affected extended families caring for orphaned children become poorer and lack essentials of life e.g. material assistance (food, clothing), legal documents (ID documents and birth certificates), housing, and emotional support. These needs are explained as follows:

4.2.3.1. Material assistance

Extended families caring for Aids orphans need a lot of support. They have to deal with grief as well as survival. They are usually unemployed or on pension or secured part time jobs. They have needs such as food, financial support and nutrition. Due to poverty and material difficulties, families depend on welfare for

food as well as FBOs rendering services within the community. To indicate the need for material assistance, a statement from one interview is as follows:

What I need now is the clothes, school uniform and food. The money I receive from my part time jobs is not enough to buy balanced diet. We only eat what is available at that time. These children have to go very early to school so that they can get a cup of soup and bread from the school feeding scheme. I cannot afford to prepare breakfast for them. The feeding scheme also provides lunch for them at least I have to struggle to prepare one meal at the house for us. It is disaster during school holidays.

This is an indication of the challenge faced by families, reduction of number of meals and thus confirms the studies conducted by Chege and Vermaak (2004). According to UNICEF (2004), it is also reported that the drop out rate in school among orphans is high because most of them cannot afford school fees and uniforms. In this case the children rely on the school feeding scheme to augment one meal they get from home at night. Proper nutrition helps give every child the best start in life, as children have the right to adequate nutrition.

4.2.3.2. Legal documents

The Government's poverty alleviation measures include allocation of social assistance in the form of cash grants to caregivers of children who qualify. The basic requirement is the South African birth certificate and bar coded identity document for the applicant which is the care giver in this case. Most of the families struggle to get these documents due to various reasons like the following respondent:

I am unemployed at present with extra two children in my house who need food and clothes as well as I have to pay for their school fees. I struggled to get their birth certificates because their mother never registered their births. I went to the welfare department to ask for assistance where they gave me money to apply for the certificates

since I could not afford to pay transport to Home Affairs. I still have to go and collect them from Home affairs. The process is so demanding because I had to go to the hospital where they were born to get proof they were born in South Africa and then a letter from the school where they attended grade one and submit both documents to home affairs. I made three trips to home affairs in Strydompark and is money to get there which I do not have.

Extended families are struggling to get proper birth certificates in order to apply for social grants. Government grants are the main contribution to a lot of families in the form of child support and foster care grant. Some already have access to these grants whereas others are still struggling with documents or waiting for approval of their applications whereas others cannot get access to them. They lack money to travel to government offices where they will be assisted. It becomes a challenge for someone who cannot afford food to be able to afford transport money to Home Affairs and apply for a birth certificate. This is why some of the children do not have necessary documents like birth certificates. On the other hand the issue of citizenship becomes a hindrance for children to get relevant documents. Hereunder is a statement from one of the respondents regarding legal documents due to citizenship:

I am struggling to apply for this child's birth certificate since I have Botswana documents but he was born in this country as a result he qualifies to get the benefits. My sister was married to a South African guy who left her with this child. She could not go back to Botswana because her life was here with her children. The father of these children, I heard he is also dead but I could not confirm anything since I did not know him well. I am struggling with these children because I am a foreigner. I was told I do not qualify to apply for any grant because the basic requirement is a South African identity document which I do not possess. These children are South Africans now they cannot benefit because of my citizenship. Does this mean I have to get somebody to apply for their documents and for the grant as well?

In this case, the extended family member caring for children is struggling to get

documents for them due to citizenship. In the meantime, whilst dealing with this issue of citizenship, the process to apply for children's certificates and social grants is delayed and these children become victims of the system. This is due to the fact that she is a foreigner and children were born within the country.

4.2.3.3. Housing

Kyasands is an informal settlement and most of the houses are shacks. There are no permanent structures in this area. Families have no privacy due to lack of enough accommodation. Children share rooms with adults and privacy between boys and girls is also lacking. Here is a statement from a respondent regarding accommodation:

I occupy this two roomed shack with my four children and my husband. After my sister's death, I had to take in her two boys. There is a problem with privacy since I have two teenage girls and they need their space. It becomes very difficult for them with boys in the same room. My husband and I find it difficult to be intimate with children and teenagers around. We have to adjust to this, what choice do we have?

This family really needs proper accommodation. Teenage girls and boys need their privacy and it is difficult with this family. The situation is not healthy for the development of these children. Parents have to compromise their relationship and this also might be risky for their marriage, unless they get some finances to extend their shack and have extra rooms for girls and boys and they also have their own room as parents and not share a room with children. Housing is a basic need for every family.

4.2.3.4. Emotional support

Extended families affected by HIV/Aids need support in ways that enable them to stay together and maintain their homes. Support efforts to families are primarily

community driven and owned, or at least community supported with external assistance. Apart from the religious and burial groups, support of the family members is with the local support groups. Some of the extended families are despondent, emotionally distressed due to loss and need support. They form groups assisted by professionals where they encourage and support each other especially in times of bereavement. New members of the group who are still struggling to accept the loss of their loved ones, are assisted by those who already accepted their situation to go through the grieving period by sharing information and personal experiences, offering support and encouragement. According to one respondent, her personal experience is stated as follows:

There is a group formed by social workers for all mothers or guardians who take care of orphans. We meet every second week on a Friday where we share our problems and achievements in order to build and encourage each other. Since I joined this group I am encouraged because at least I managed to get information about the grants. I only had information about child support grant and not foster care grant as well as the care dependency grant. I only heard rumours that you cannot receive two grants from the government but that was a lie. Due to this group I got very important information and I know which steps to take. They also helped me to understand that it is normal to mourn for a long time.

Due to the nature of the problem the respondents face, they get support from different sources. In this case the respondent got support from a group which empowered her and gave her some information and encouragement. The support differs from emotional, spiritual, financial and materially during time of need. It is with support groups where care givers can discuss their concerns and ask questions. They get opportunities to share information about available services. According to Nzimande (1996), the support system in black communities is based upon values, and socialisation patterns through which a feeling of social responsibility and reciprocal support is created and practiced.

4.2.4. SERVICE RENDERING

Service rendering refers to service volunteered by individuals, organisations, government departments with different professionals to benefit a particular community. It is an unpaid (free) service performed to benefit the public. People become involved in a community service rendering for many reasons with main focus being to empower communities in order to improve their standard and quality of living. In this study the following kinds of service were rendered to the community: the department of social security assisted people with applications for social grants, Non-governmental and faith-based organisations offer material assistance, professionals like social workers and psychologists offer counseling services to bereaved children and their families as well as assessments, other organisations offer training as empowerment services. The department of home affairs assists with applications for legal documents (birth certificates and Identity documents).

4.2.4.1. Social Grants

The government's poverty alleviation programme includes the allocation of social grants to those who qualify. This includes issuing of cash foster care grants to extended families caring for orphaned children under the age of 18 years, as well as child support grants to children below 14 years of age. The amounts differ from R220 to R680. There are some people who do not benefit from this service because they lack access to them due to various reasons which included ignorance, lack of relevant documents or lack of means to reach service providers. The following respondent expressed her feelings regarding service rendering in terms of grants as follows:

I knew nothing about the grants except for old age pension. I only heard about them the

first time when I went to ask help at the social workers' offices. I heard rumours that they give orphans money so I also went to try my luck because I am struggling to make ends meet with this child.

The problem that existed with this case was that community member did not know about the availability of this service due to ignorance. She went to welfare to try her luck and not assistance; this is an indication of ignorance. The basic requirement with getting the social grant is submission of relevant documents which most of the families struggle to access. It has been found out that Government grants are the main contribution to a lot of families. Social security officials have the responsibility to assist with application for different social grants. Most of the extended families are not well informed about social grants as confirmed by Vermaak and Mavimbela (2004). This situation is a challenge to the Social Security Department that there are some people who are still not aware of the services they render. On the other hand there are those who benefited from the services rendered by the government like the following respondent:

Apart from my old age pension I receive from Social Security, I also receive foster care grant for these children. Our government is actually taking care of my family. Imagine if I was not getting anything, it will be very bad. Now I can afford to buy food and clothing for them. Thank God for our Government.

In this case life is different and has changed to this family due to financial assistance from the government. Unlike the previous respondent, this respondent is informed and making good use of the government services available to her.

4.2.4.2. Material Assistance

Extended families caring for orphaned children come from resource poor and vulnerable communities characterised by poverty and multiple social needs. According to the findings, the respondents receive services mostly from the Non

Governmental Organisations (NGO) and Faith Based Organisations (FBO). Amongst the services they receive, this includes material assistance. FBOs are running feeding schemes and soup kitchens at schools. Here is a respondent's experience with material assistance.

The school assisted me with their feeding scheme because now I have a responsibility to prepare one meal only at night. They have soup and bread in the morning at school and they also provide them with lunch.

Those children who are needy and orphans benefit from this service since some of the children cannot afford lunch boxes to school. This service contributes greatly to the development of the children at schools by providing them with nutritious meals which include soup in the morning when they arrive at school and lunch. This situation in this family is confirmed by Chege, Vermaak and Mavimbela (2004) when they noted that extended families are also faced with increased expenses which lead to deterioration of quality of households' diet and reduction in the number of meals. The family in question depends on a feeding scheme and prepares only one meal per day.

4.2.4.3. Professional support

The psycho-social support provided through counseling strengthens the sense of individual responsibility needed to accept new information and change lifestyles. Respondents manage to accept their loss due to support they get from counselors, social workers and psychologists who also do assessments for children affected by the grieving process and end up developing behaviour problems. In counseling families caring for Aids orphans, service providers assist them to define for themselves the nature of the problems they are facing. A statement from one respondent follows:

I was so worried about this child with his lack of respect for other people but since the visit to the psychologist now I understand why he is like this. The counseling assisted us a lot.

Counseling involves much more than an occasional informal discussion. The need for continued support and help with problem solving is also very crucial for most of the families who care for orphans with personality problems due to loss of their parents. Through counseling families are enabled to make realistic decisions about what they can do to reduce the impact of problems on themselves and the children they are taking care of (UNICEF, 2004).

4.2.4.4. Training

The extended families caring for Aids orphans experience a lot of problems like dealing with problematic children they take in. In this study most of the families attended training at FAMSA. They were given parenting, and problem solving skills and specifically how to deal with children of different ages. Here is an example of one respondent's experience:

I took it I knew how to deal with children until this one came to my house that is when I saw the need to get training from FAMSA because he was too much for me with his demanding character.

The respondent decided on her own to seek assistance and got empowered. Now she is able to treat the child accordingly without judging him due to the training she received.

4.3. SUMMARY

Extended families in this study were led by grandparents (especially grandmothers), aunts and uncles. The grandparents had an opportunity to care for the orphaned children's parents before they died of HIV/Aids. Even though there were some children who moved from their homes to stay with relatives, most of them did not have to adjust to new environments and new ways of living.

Those who were forced to adjust to new ways include adjusting from urban life to informal settlement way of living where there are limited or no resources and services. Due to this change, some of these children developed behaviour problems which affected their care givers.

According to Webb (2000), due to loss and grief, children might develop behaviour not acceptable to their care givers. He further indicated that children grieving for dead parents are often stigmatised by society through association with AIDS. The distress and social isolation experienced by these children, both before and after the death of their parent(s), is strongly exacerbated by the shame, fear, and rejection that often surrounds people affected by HIV and Aids. Once a parent dies, children may also be denied their inheritance and property.

Some of the children developed anti social behaviors due to loss which include even attempted suicide and isolation from other children. Others are too demanding and this causes tension in their families, as other children feel neglected. Some extended families lost out on services available to them due to lack of knowledge. This included availability and application for social grants and the requirements thereof. Those with access to these grants seemed to be their only source of income in the form of old age, foster care and child support grants.

As part of service rendering CBOs, NGOs and FBOs provide material assistance to families in the form of clothes, food, school uniforms and school feeding schemes. Due to poverty most of the families live in shacks which are poorly furnished. They lack privacy in these shacks but that is what they have as assets. Due to poverty and lack of source of income they do not have any savings. According to the findings, the respondents receive services mostly from the Non Governmental Organisations (NGO), Community Based Organisations (CBO) and Faith Based Organisations(FBO). The services include bereavement counseling, information about grants, foster care placements, spiritual upliftment as well as material assistance.

CHAPTER 5

CONCLUSIONS AND RECOMMENDATIONS

5.1. INTRODUCTION

HIV/Aids does not only impact the medical field, but also affects the psychological and social realities of people which include families caring for the sick people, their friends, caregivers or members of the public (Jackson, 2002). The Aids epidemic has had far reaching effects on families. Many of the most striking images of the HIV epidemic are of families which include grandparents surrounded by a number of grandchildren and female headed families (UNICEF, 2004). The HIV/Aids pandemic is a chronic terminal illness that forces individuals and their families to cope with an uncertain progression of disease, complicated medication regimes and the grief related to the loss of family members. Unlike other chronic illnesses, HIV/Aids is further complicated by the stigma attached to it.

Aids reduces productivity, depletes scarce public and private capacity, raises cost of doing business, deepens poverty, diminishes school enrolment, overwhelms health systems, impairs human rights, weakens food security, erodes social capital and progressively crowds out government development investment (Desmond & Gow, 2001).

The impact of HIV/Aids extends beyond those living with the virus, as each infection produces consequences which affect the lives of the family surrounding an infected person. The family is the fundamental group of society; the natural environment for growth and well-being of all its members and particularly children orphaned by HIV/Aids. The families, especially extended families caring for orphaned children need to be afforded the necessary protection and assistance so that they can fully assume their responsibilities within their households. It has been indicated in this study how extended families manage to live with their orphaned children. Below is an indication of the conclusions reached in terms of

the methodology applied during the study, literature review as well as the key findings.

5.2. CONCLUSIONS IN TERMS OF RESEARCH METHODOLOGY

Analysis of extended families caring for HIV/Aids orphans was the main goal of this study and the objectives were identifying their problems, needs and assets as well as types of services available within their communities. Grand parents, uncles and aunts caring for these children were interviewed who shared their experiences as indicated in the key findings. A qualitative research method was used to collect data from the respondents. The researcher chose the qualitative method because she wanted clear, full information from the respondents. The researcher came to a conclusion that the qualitative method was truly a tool that can be used if one needs full information about a phenomenon. The respondents are not restricted to certain ways of giving information but were assisted to voluntarily give information due to open ended form of questioning during interviews.

5.3. CONCLUSIONS IN TERMS OF LITERATURE REVIEW

Through literature reviewed on HIV/Aids the researcher came to the conclusion that HIV/Aids is the most serious health problem in the world today and the leading cause of death to young generations as it is also confirmed by UNAIDS and WHO (2000) that Aids is the leading killer of human race. Sub-Saharan Africa, especially Southern Africa is the region in the world hardest hit by HIV/Aids.

As indicated in the literature review (chapter 2), the Global Aids report (2008) indicate that South Africa has the sixth highest HIV/Aids prevalence rate in the world. In a country of 48 million people, about 5.7 million are HIV positive (11.1% of the population). There are approximately 750 000 people with full-blown AIDS. The country's infection rate has not decreased despite robust efforts to spread

information about HIV-AIDS. In 2006 alone, there were close to 550 000 new infections.

It is noted in The Global Aids report (2008) noted that 320 000 people died of Aids related sicknesses in South Africa alone by 2005. In 2007, 5.7 million were living with Aids in South Africa and almost 1000 deaths occurred everyday. Children below two years become orphans and that raises a need for care givers. Another concern is the escalating number of orphans which was 1.2 million aids orphans in South Africa in 2005, 1.4 million in 2007 compared to 780 000 in 2003.

These statistics led the researcher to a conclusion that, if the scourge of HIV infection and full blown Aids grows in South Africa like this, over the next couple of decades, inequality will probably rise as Aids lowers growth and slices a way through the poor and disadvantaged in South Africa. Such an occurrence would invalidate the long-term goals of the country's public policies in almost all its sectors, which have poverty alleviation as one of the constant sub-themes.

According to UNICEF (2004) in sub-Saharan Africa, 90 per cent of children orphaned by AIDS are cared for by extended families, with little or no outside support. It is therefore concluded in this study that families and local communities carry the main burden of care and support for children orphaned by Aids. The impact on extended family members, thus grandparents and relatives, and especially on children, is severe, and in many cases, the burden has become too much to bear.

The researcher came to a conclusion that no amount of care and attention can take away the pain that children feel after the death of their parents but it is apparent that orphans greatly benefit from the care available within their extended families and communities. There is no need for them to adjust to new environments and learn new ways of living. They stay with their relatives (grandparents, uncles and aunts) they knew even before their parents died of Aids which brings an element of stability within their families. According to the

Department of Social development (2002) orphans cope better if they remain in familiar surroundings, in family units even if not their biological families. If extended family network and communities are to continue to play this role, it is essential they receive social and material support from government, development agencies and the private sector.

5.4. CONCLUSIONS IN TERMS OF THE FINDINGS

In this section is some of the conclusions reached by the researcher in terms of assets owned by extended families, challenges faced by extended families which included behaviour changes of the orphaned children, stability within their families, increased family expenses and problems caused by stigma to families caring for aids orphans as well as the extended family needs and services rendered to them. Conclusions reached regarding findings are discussed as follows:

5.4.1. Assets

The extended families caring for Aids orphans had their own way of surviving and they also had assets to make a living. Those included physical assets (such as shacks, furniture, battery operated radios and television sets), social assets (their family networks, associations within the community) and financial assets (stockvels for saving money and burial societies, as well as social grants from the government). This brought the researcher to a conclusion that no matter what state of life a person may live they always have their own ways of surviving and coping with their situations. In this case without proper services, unemployment, no electricity, families made means to make a living as confirmed by Patel (2005) that assets are considered to be shocks of different types of capital that can be used directly or indirectly to generate livelihood. Families depend on their assets for survival (Carney, 1998).

5.4.2. Challenges

5.4.2.1. Children behaviour problems

Extended families were experiencing problems with the very orphaned children they care for as some of them had behaviour problems caused by grief. It is therefore concluded that it is not only the orphaned children who are affected by the grieving but also extended families changed their attitude and paid more attention to the orphaned children. Having to deal with the behaviour of the child also affect theirs because their patience is also tested by these children who are disrespectful, aggressive and antisocial towards their care givers, other children and their educators.

It can also be concluded that the health of care givers can also be affected when they try to accept and tolerate the anti-social children. They can end up being depressed and in that way their health is compromised. Jackson (2002) identified a trend that children whose parents die of Aids in towns are usually taken back to the rural areas. They have to adapt to loss of parent(s) as well as to rural life. The security and stability of their family is disrupted and there is no social safety net or mechanism to help them through this transition period thereby increasing risk behavior among them which ultimately affects their families..

5.4.2.2. Stability

The continuation of the family unit despite the alteration brought about following the death of parents goes a long way in alleviating the pains of the children brought by trauma. It is concluded that the sense of having a family is very important for the children and this helps to build a real sense of identity and belonging as well as bringing stability in their lives. Nothing can improve on the role which the extended family plays in the care of orphaned children, thus the researcher concludes that there is a need to strengthen the capacity of extended

families to care for these children. This study confirmed the findings by Mutangadura (2000) that when parents die, it has a devastating effect on the capacity of families to remain intact. Grandparents (in particular grandmothers); seem to take over the parenting role with multiple grandchildren.

5.4.2. 3. Increased family expenses

Due to increased family members, expenses also increased within families. For this reason, the researcher reached a conclusion that the expenses do not only affect the families caring for Aids orphans but government also. As the number of orphans increases, so do the number of applications for social grants as well and this means increased expense for the government. Loss and shortage of income, rising expenditure and need for adjustment of household management systems may produce internal tension and conflict (Kabir *et al.*, 2000) because care givers try by all means to make orphans happy and neglect their own children. Vermaak and Chege (2004) noted that extended families also face increased expenses which lead to deterioration of quality of households' diet and reduction in number of meals since they cannot afford due to lack of funds.

5.4.2. 4. Stigmatisation

Some of the extended families could not depend on the community for support, as families taking care of orphans are often stigmatised and rejected by their own communities (Jackson, 2002). Some extended families staying with HIV/Aids orphans are stigmatised and ostracised. This usually results in a loss of respect within the community (UNAIDS, 2004). Fear of discrimination leads to families isolating themselves from the community rather than seeking help. They therefore could not benefit from the services offered in their communities. This situation led to the conclusion that HIV still has a stigma attached to it even after so much education and awareness campaigns within communities and it is an

indication that service providers still have a lot of work to do in terms of continuing with their education.

5.4.3. Needs

According to the findings in this study extended families lack essentials like clothing and food. In this section conclusions are reached in terms of material assistance and support that extended families need.

5.4.3.1. Material assistance

Food, clothing, and school uniforms were identified as needs for extended families caring for Aids orphaned children. Some of them needed proper housing as the shacks they stay in were not big enough to accommodate them. Financial assistance for school fees and transport was also a burning issue as schools were very far for the children. According to UNICEF (2004), it is also reported that the dropout rate in school among orphans is high because most of them cannot afford school fees and uniforms; some drop out because of absenteeism to attend to household chores. It is concluded that extended families had to make sure their basic needs were catered for in order for them to be able to care for the Aids orphans. Processing of the government grants was the only hope for most of the families for them to be able to meet their needs

5.4.3.2. Support

It is concluded that the need for continued support and help with problem solving is also very crucial for most of the families who care for orphans with personality problems due to loss of their parents. It should be a key aspect in counseling relationships with these children. According to Nzimande (1996), the support system in black communities is based upon values, and socialisation patterns through which a feeling of social responsibility and reciprocal support is created and practiced.

5.4.4. Service rendering

Services within communities are offered by Non Governmental Organisations, Community and Faith Based Organisations in the form of material assistance, psycho-social support as well as training. Respondents get support and assistance in terms of applying for legal documents (identity documents and birth certificates) as well as application for social grants. Those who cannot cope with grief, receive counselling and assessments from social workers and psychologists. Their local pastors and churches assist with spiritual upliftment.

The services to support extended families caring for orphaned children were given in ways that enable them to stay together and maintain their homes. Essential services for children and their families were not effectively reaching those that need them the most. Documentation was considered a key concern in especially as processes to obtain birth certificates are costly and time consuming. It is therefore concluded that, without birth certificates, caregivers can often not access food parcels and other services they are entitled to and in that case the orphaned children end up being the victims of the systems since they are the ones who suffer. Most of the extended families are not well informed about social grants as confirmed by Vermaak and Mavimbela (2004), therefore the quality of service must be improved for the benefit of the orphaned children and their care givers especially requirements to apply for legal documents and procedure in applying for social grants that take a long time without any alternative assistance from the government pending applications.

5. 5. RECOMMENDATIONS

The following recommendations aim to strengthen families to provide care and support for orphaned children in the context of HIV and Aids. They are directed at the service providers to enhance their efforts in rendering effective quality service which include the recommendation in terms of training, psycho-social support, networking, destigmatisation and lobbying. They are outlined as follows:

5.5.1. Training

Provision of training family life skills and opportunities for development should be made available for extended families caring for HIV/Aids orphans. Support offered to those families may be utilised to improve their quality of life. Training for those in communities who interact with extended families can allow more people to contribute to provision of quality care and offer support. Such training can also reduce the fear and discrimination which result from misunderstanding and misinformation. Training does not only provide education or information but also encourage confidence and self esteem in those involved.

5.5.2. Psycho-social support

It can also be concluded that psycho-social support provided through counseling, strengthens the sense of individual responsibility needed to accept new information and change lifestyles. In counseling families caring for Aids orphans, service providers assist them to define for themselves the nature of the problems they are facing, so that they can make realistic decisions about what they can do to reduce the impact of these problems on themselves and the children they are taking care of (Johnson & Dorrington, 2001). Counseling involves much more than an occasional informal discussion.

According to the Department of National Health and Population Development (1998), professionals play a vital role in the control of HIV/Aids since they have special responsibility of educating the public through awareness campaigns. It is therefore recommended that social workers mobilise psycho-social support to help meet informational and training needs of families and ensuring that the needs of children and their families are met.

5.5.3. Networking

The majority of orphaned children experience psychological trauma and display behavior problems, service providers working with them should be able to network with other professionals like psychologists and psychiatrists in order to offer a holistic service. As part of networking, service providers need to

coordinate or facilitate succession planning and will writing in HIV affected households, to ensure children's rights are upheld to inheritance after parent's death (Chege, 2002).

5.5.4. Destigmatisation

Programs (developed by different service providers) should seek to strengthen the affected family units and their ability to cope with added strains HIV/Aids inflicts. Programs should provide opportunities for families to remain productive without creating discrimination or causing further possible stigma. Regarding the issue of stigma, workshops should be conducted with families, including older carers, men, women, and children, on the impacts of stigma on individuals living with HIV, and their families. Such workshops should integrate voices from all family members suffering from stigma, and discuss the specific challenges impacting on the family wellbeing.

The workshop should identify and address means of how to decrease the impacts of stigma on families (e.g. through referring family members to specific support groups such as psychosocial care, or to campaigns) and to identify the role other families can play in decreasing the burden of ostracised families. In addition, effectively addressing stigma and discrimination within the community and its different groups is important, as it can enable the broader community to identify and mobilise resources necessary for families heavily affected by HIV/Aids; decreasing their dependency on service delivery.

5.5.5. Lobbying

Lobby opinion leaders in the community (faith leaders, traditional leaders, local councillors, head teachers, local media organisations and practitioners) to speak out on issues of stigma and discrimination, and values, and to promote respect and care for all.

5.6. FINAL CONCLUSION

The extended families were analysed and it was identified that they play a vital role in caring for the Aids orphans. They experience problems in caring for these children since most of them cannot afford to meet the needs of their families due to unemployment. This causes a burden in their lives as they live under poverty and most of them depend on government grants for survival.

To date more attention is paid to HIV prevention and to treatment of opportunistic infections and even distribution of antiretrovirals than to the fundamental nutritional and primary survival needs of the poor people affected by Aids. While orphaning is on the increase and will have risen in most countries, relatively few children would seem to be living in situations of extreme vulnerability and put stress on extended families. One of the primary issues is to support extended families that care for children orphaned by HIV/Aids, while grieving the loss of their loved ones. As young and adult people die of Aids like this, it will become a challenge to the government since this system will be saturated and residential care will be the only option for orphaned children after their parents die of Aids.

Government funding and programming for OVC must include support for caregivers so that children may be raised by their community versus being institutionalized in an orphanage where often there is a far lower care-taker to child ratio and where children simply do not fare as well.

Support for the caretakers is an essential step in ensuring that children receive proper care and attention. In many cases, orphans are taken in by grandparents who no longer work and, therefore, no longer earn a wage. Even when the caretakers do have money coming into the household, they were often in an impoverished situation before the addition of dependents to the household. The combination of chronic poverty and the HIV/AIDS epidemic have greatly stressed and drained community resources.

REFERENCE LIST

Babbie, E. & Mouton, J. (2001). *The Practice of Social Research*. Cape Town: Oxford. University Press.

Carney, D. (1998). *Sustainable Rural Livelihoods: What Contribution Can We Make?* London: Department for International Development

Centre for the study of AIDS. *(2001)*. *AIDS Review,* Pretoria: University of Pretoria.

Chege, J., Mavimbela, N. & Vermaak, K., (2004). *Challenges faced by Households in Caring For Orphans and Vulnerable Children:* A Nelson Mandela Children's Fund Research project, Johannesburg.

Child Health Unit. (1998). *HIV/AIDS and the family: A Clinical Guide*. Cape Town: University of Cape Town.

Cohen, J. (2000). *Approaches to the management of disruptive behaviours*. Interventions in dementia care: Toward improving quality of life. Edited by Lawton MP, Rubinstein RL. London: Springer.

Creswell, J.W. (1998). *Qualitative Inquiry and Research Design: Choosing Among the Five Traditions.* Thousand Oaks, CA: Sage.

Creswell, J.W. (2003). *Research Design: Qualitative, Quantitative and Mixed Methods Approaches,* 2nd Ed. Thousand Oaks, CA: Sage.

Crowley, M.L. (1995). *Crisis as Challenge*: counseling counselors, persons living with HIV/AIDS and survivors. *Journal of Social Development in Africa*, 10, 35-52.

Denzin, N., & Lincoln, Y. (Eds.). (1998). *The landscape of qualitative research***.** Thousand Oaks, CA: Sage.

Denzin, N.K. & Lincoln, Y. (2000), *Collecting and interpreting qualitative materials. The Discipline and Practice of Qualitative Research*. Thousand OAKS, CA: SAGE.

Department of Social Development (2002). *National Guidelines for Social Services to Children Infected and Affected by HIV/AIDS*. Pretoria.

Desmond, C. and J. Gow. 2001. *The Cost Effectiveness of Six Models of Care for Orphan and Vulnerable Children in South Africa*. Pretoria: UNICEF.

De Vos A.S., Strydom H., Fouche C.B., & Delport C.L.S. (2002). *Research at Grassroots: for the Social Sciences and Human Service Professionals*. Van Schalk, Pretoria.

De Vos, A. S. (2005). *Research at Grassroots. A Primer for the Caring Professions.* Pretoria: Van Schaik.

Ewing, D. 2000. *'Children and AIDS: Prevention Means Access to Treatment Now*'. Children First 4(32):4.

Foster, G. (2000). *Responses in Zimbabwe to children affected by Aids*. SAfAIDS News 8:pp.2-7.

Fox, S. (2000). *Hidden needs of children: Psychosocial support for children affected by HIV/Aids*, International Aids Conference 14: Abstract No. WePef6871.

Hunter, S. & Williamson, J. (2000). *Responding to the needs of children orphaned by Aids:* Discussion paper on HIV/Aids care and support. Arlingtons Health technical Services Project for USAID.

Jackson, H., Mukurazita, D. & Mutangadura, G (1999). *A review of household and Community responses to the HIV/AIDS epidemic in the rural areas of Sub-Saharan Africa.*

Jackson, H. (2002). Aids Africa: *Continent in crisis.* Frontline Electronic Publishing: Harare, Zimbabwe

Johnson, L. & R. Dorrington. 2001. *The Impact of AIDS on Orphan hood in South Africa: A Quantitative Analysis.* Cape Town: Centre for Actuarial Science, University of Cape Town.

Kelle, U. (1998) *Sociological Research online*, Vol 2, No.2
Kendall, J. (1999). '*Axial Coding and the Grounded Theory Controversy*'. Western journal of Research. 21(6):743-57.

Kübler-Ross, E (2005). *On death and dying.* London: Tavistock.

Lincoln, Y., & Guba, E. (1985). *Naturalistic inquiry*. New York: Sage.

Michael, K. (2001). *Understanding the urban impact of HIV and Aids-associated Orphanhood, in Aids orphans in Africa: Building an urban response,* 23-28 Proceedings of forum held in Johannesburg on 21 July 2000. Johannesburg: Centre for Policy Studies.

Modo, I.V.O. (2001). *Migrant Culture and Changing Face of Family Structure in Lesotho*. Journal of Comparative Family Studies, vol.32, no3, pp443-52.

Moller, V., & Devey, R. (1995). *Black South African Families with Older Members: Opportunities and Constraints.* South African Journal of Gerontology, vol.4, no.2, pp.3-10.

Moyo, O.N. (2001). *Dealing with work in its context : An analysis of household work and provisioning strategies in Bulawayo, Zimbabwe*, PhD Thesis, Heller Graduate School, Brandeis University.

Patel, L. (2005). *Social Welfare and Social development in South Africa*. Oxford: University Press.

Robinson, M. E. & Riley, J. L. (2000). *The role of emotion in pain*. In R. Gatchel & D. Turk (Eds.), *Psychosocial factors in pain: Critical perspectives* (pp. 74–88). New York: Guilford Press.

Scales, P. C., & Gibbons, J. L. (1996). *Extended family members and unrelated adults in the lives of young children:* A research agenda. Journal of Early Adolescence, 16, 365–389.

Steinberg, M., Kinghorn, A., Soderlund,N., Schierhout, G., & Conway.S. (2000). *HIV/AIDS: Facts Figures and the Future. In South African Health Review 2000*, Durban: Health Systems Trust.

Steinberg, M. (2002).*Hitting Home: How households cope with the impact of the HIV/AIDS epidemic, a survey of households affected by HIV/AIDS in South Africa.* Washington DC: Henry Kaiser Family Foundation Trust.

Strauss, A. & Corbin, J. (1998). '*Open Coding'. In Basics of Qualitative Research.* Thousand OAKS, CA: Sage (Blackboard).

Strubert, H. & Carpenter, D. (1995). *Qualitative Research in Nursing – Advancing the Humanistic Imperative*. Philadelphia: Lippincott Company.

UNAIDS, (2004). *Global Estimates of HIV and AIDS, chapter 4: The impact of AIDS on people and societies*.

UNAIDS, (2006). *Report from a consultation on the Socio-Economic Impact of HIV/AIDS on Households.*

UNAIDS, (2006). *Report from a consultation on the Socio-Economic Impact of HIV/AIDS on Households.*

UNAIDS, (2008). Report on the global AIDS epidemic

UNDP, (2003). HIV/AIDS Results.

UNICEF, (2004). *Children on the Brink 2004*, UNICEF, New York, 2004, p. 11.
Webb, D., (1997). *HIV and AIDS in Africa*. London: Pluto Press.

Webb, D. & Paquette, S. (2000) "*The Potential Role of Food aid in Mitigating the Impacts of HIV/AIDS: The Case of Zambia*" in *Development in Practice.* Vol.10, No.5, pp. 694-700.
WHO (World Health Organization), (2001). *The world health report-Mental health*: New Understanding, new hope.

Appendix A

Informed Consent Letter

Dear Respondent

HIV/Aids reached epidemic proportions in South Africa. According to the World Health Organization (WHO), it is one of the number one killers in sub Saharan Africa, leaving behind most of the children orphaned and without any means of support. According to reports, more than 12.1 million children in sub Sahara Africa are orphaned by Aids (UNICEF, 2000).Because you are a care giver, an extended family having an Aids orphan in your care, I am asking your help by sharing your personal experience in this instance. The challenges you come across, and the importance thereof of caring for Aids orphans. Your participation in the study is voluntary and you may refuse to answer any question. Only a few extended family members will be part of this study, so your participation is very important to this study.

The answers you provide will be confidential. Though some of your responses may appear in my dissertation, your identity will not be revealed in my study or other writings or publications related to the research. The interview schedule and your responses will be destroyed once the information you provided have been summarized. For purposes of this study I will need you to provide as much information as possible in terms of your experiences for the benefit of this study guided by the interview schedule that I will use.

I thank you for your understanding, and appreciate your cooperation.

Sincerely,

Kedibone Mpoza _____

(MA Social Work Student) (Respondent)

APPENDIX B

INTERVIEW SCHEDULE

1. RELATIONSHIP

a. What is your relationship with this child/ren?

They are my sister's sons. I am their uncle.

2. PROBLEMS / NEEDS

a. Briefly describe your experience in terms of taking care of an HIV/AIDS orphan.

It is painful to watch my nephews like this. They are used to city life now they have to adjust to our informal settlement lifestyle and share a shack with us. This is the change they have to adjust to because there is nothing we can do. They never complain about anything, but I think my sister has to take them because I have my own six children plus the two of them. It is too much for me and my wife is starting to complain but that is not the point. The accommodation is not enough for us all.

b. What kind of material assistance do you need?

What I need now is the clothes, school uniform and food. The money I receive from my part time jobs is not enough to buy balanced diet. We only eat what is available at that time. These children have to go very early to school so that they can get a cup of soup and bread from the school feeding scheme. We cannot afford to prepare breakfast for all of them. The feeding scheme also provides lunch for needy children at least. I have to struggle to prepare one meal at the house for us. It is disaster during school holidays.

Behaviour problems
- lack respect
- Abuse drugs
Psychological problems
Personality problem

c. What specific problems do you experience with this orphaned child/ren?

My problem is that the other one is now too much. He never listens when adults talk to him. He is always angry at everyone. Even his teachers complain that he is always involved in fights at school. Anyway, he was not like this when his parents were alive. He is now associating himself with wrong children. He is stubborn, smokes dagga all in a short space of time. The psychologist said that I must bear with him but I think he is taking advantage of me. I used to smack him but now he is tall I cannot do that anymore. How long am I supposed to bear with him? This is too much!

d. What are the challenges of having an additional member within your family?

Financial Need
- family expenses

Food Security
Service delivery

I am experiencing some financial difficulties since I took these children into my house. I am a labourer and the money I received used to be enough for me and my children. If I can get an extra source of income our problems will be limited. The expenses include medical expenses. Yes we do not pay for them but to collect them we have to pay transport to town since we do not have any hospital nearby offering Art's for children. We can only get them from the hospital in town. I hope application for grant will be processed soon it will help me to take this boy for follow up and collect his treatment on time. I will also be able to buy a suitable diet for him.

3. RESPONSE TO CHALLENGES

a. How do you address the challenges and problems you are experiencing within your family?

extended relation
Social Asset
Counselling

My family is my support system when I need help. My elder sister usually comes to visit and talks to this young boy to behave. Otherwise I talk to them and smack

them if necessary when they misbehave. In terms of material things we receive monthly food parcels from the Home base care givers when they come to follow-up their patient. Our church as well is so supportive to our family. All families with orphaned children receive some food parcels from the church every month end. There are some people who sometimes also volunteer to pay for these children's school fees from our church. This is so great.

4. ASSETS

a. How do you manage to maintain your family?

We are having a stockvel in our area consisting of fifteen women. We contribute some money every month which we share at the end of every six months. What happens is, we take the money to the post office. After six months we go and withdraw a certain amount and we buy grocery in bulk and share it. This is assisting me a lot and we never struggle in terms of food. I struggle with other things with the foster care grant I receive. I also use part of this grant to contribute to our burial society in case crisis happened.

b. Describe your relationship with your neighbors.

My nephews are suffering. Even myself I cannot say I have accepted the death of my sister. I still miss her a lot. What makes this more difficult is the fact that my neighbours are isolating us. They call us names due to the fact that my sister was killed by Aids. They do not want the boys to play with their children saying they will infect them. This is a very difficult situation because you always think and suspect that people are talking about you.

c. Explain the benefits you get from interest groups you belong to.

My perception of life changed a lot since I started attending the foster care parents' support group at the clinic. We talk about our problems, share our difficulties and help each other on how to approach situations in terms of caring for orphaned children. I will not stop attending this group because I gained a lot

grief empowerment Support
of information from there as well as emotional support because I struggled to
grief
accept the loss.

d. Briefly describe your living conditions within your house.

Physical effects
Information
Leisure time
No privacy

physical aspect
I have been living in this shack for the past fourteen years. We do not have
Physical aspect physical aspect
electricity that is why I use the solar system for my TV, I have a radio using car
Information
battery to listen to news. The TV uses more power that is why I prefer to listen to
Grief
the radio during the day. We will be moving to the RDP houses in Cosmo City
Leisure time
very soon where we would be able to watch TV all day because there will be
physical aspect
electricity. I sleep on the sponge bed in my room with my wife and all these
No privacy
children have to spread themselves on the floor during the night in another room
which we use as dinning room and kitchen as well.

5. SERVICE RENDERING

a. Explain the kind of professional service you received for the period since you started staying with the orphaned child.

Ignorance
Empowerment Ignorance
I thought I knew how to deal with children until this one came to my house that is
Empowerment
when I saw the need to get training from FAMSA about parenting skills because
he was too much for me with his demanding character.

b. Describe your knowledge about the social grants.

Ignorance Social grant
I knew nothing about the grants except for old age pension. I only heard about
Professional assistance
them the first time when I went to ask help at the social workers' offices. I heard
rumours that they give orphans money so I also went to try my luck because I am
Empowerment Social aspect
struggling to make ends meet. I got full information from the support group I
attend.

Appendix C

PREDETERMINED GENERAL CATEGORIES TO BE CODED

1. Relationships
2. Problems/Needs
3. Experience
4. Bereavement/Grief
5. Material Assistance
6. Challenges
7. Assets
8. Support System
9. Service Rendering
10. Government grants